REPORT ON THE 1980 BUSINESS MEETING OF THE NSGC, INC.

The second annual business meeting of the National Society of Genetic Counselors, Inc., was held on September 24, 1980. Audrey Heimler, past president, opened the meeting with remarks found elsewhere in this issue. The minutes from the 1979 business meeting presented by past secretary Sylvia Rubin were accepted without additions or corrections. Niecee Singer, treasurer, presented a report on the financial status of the Society indicating that our treasury is in the black with total assets of $5436.33 as of July 31, 1980.

Lorraine Suslak, past vice president, reported on the grant received from the March of Dimes, Birth Defects Foundation. She also announced that an information pamphlet prepared by the Professional Issues Committee for individuals interested in NSGC membership has been printed and is ready for distribution.

Deborah Eunpu, editor, reported on plans for Perspectives in Genetic Counseling which include the appointment of Joseph McInerney as Assistant Editor, plans to form an Editorial Board and ways in which the format of Perspectives will be expanded.

Judith Dichter, past co-chair of the Education Committee reviewed the work of the committee. She suggested that a portion of educational programs in 1981 be planned with the upcoming certification examinations in mind. Carolyn Bay was introduced as chairperson of the 1981 national education meeting which is to be held in conjunction with the Birth Defects meeting in San Diego, June 14-18, 1981. At this time, a planning committee has been formed which will prepare a program to include invited speakers, workshops and papers contributed by NSGC members. The meeting is scheduled to begin the evening of June 18 and to continue through June 19. A more detailed announcement of this meeting will be circulated to all members in the near future.

Evelyn Lilienthal, past Membership Committee chairperson, reported that as of September 24, 1980 NSGC membership stands at 237: 194 full members; 9 associate members; and, 34 student members. There are 40 pending applications for membership. Ann Smith presented a project she is heading which will develop and publish a directory of all NSGC members. The directory will include location and contact information as well as strings of primary activities and special interests areas of (continued on p. 2)

OPENING REMARKS
1980 BUSINESS MEETING
Audrey Heimler, M.S.

Welcome to the second annual business meeting of the National Society of Genetic Counselors. We meet this year with the major organizational efforts behind us, several fine achievements to our credit and exciting prospects ahead for professional activities within the Society. In the short period since incorporation in October, 1979, the National Society of Genetic Counselors has gained recognition as a national professional society and has attracted attention to genetic counselors with a Masters or Ph.D. degree as a separate, identifiable profession.

At the time of the Society's inception the following goals and purposes were formulated:

1. to further the professional interests of the genetic counselor.
2. to promote a network for communication within the profession.
3. to deal with issues relevant to human genetics.

During this past year the program and activities of the Society have coincided with these goals as demonstrated by publication of Perspectives in Genetic Counseling, the newsletter of the Society, professional projects underway or completed, superb regional and national educational meetings and appropriate recognition in the certification process of the American Board of Medical Genetics. You will be hearing about the activities of the past year as the meeting progresses.

The theme of this year's business meeting is "Discussion". We are here tonight to discuss programs for continuing implementation of the stated goals of the Society for the coming year and for the years to come. During the next two hours the members of the Board of Directors will present agenda items and request response, comments and recommendations. Subsequent program planning will reflect the input of the discussion tonight.

One of the main purposes of the Society is to provide continuing educational programs to suit the needs of the members particularly in areas where these needs are not being met by the programs of other meetings (e.g., methodology in genetic counseling, clinic coordination, professional goals, public awareness of the genetic counseling, roles of various professionals within the overall genetic counseling profession and clinical research). Programs have been planned to provide for the heterogeneous nature of the jobs within our profession.

(continued on p. 2)
BUSINESS MEETING, continued

members. Questionnaires for obtaining the necessary data will be distributed to all members.

Phyllis Klass, Chairperson of the Professional Issues Committee, reported on past and planned projects of her committee. Sandra Schlesinger was introduced as the planner of the project to convene an international conference for the standardization of pedigree symbols and construction.

Ann Walker, chairperson of the Social Issues Committee, described her committee’s work on a project to ascertain the accessibility of genetic services through a nationally distributed questionnaire.

A report concerning the plans for the certification examinations was presented by Audrey Heimler who is a member of the American Board of Medical Genetics. Due to the large number of applicants (643 total, 200 for the genetic counselor exam) and to a promising proposal for funding, it is likely that the fees for examinations will be lower than originally anticipated. Dates for the first examination have been set for December 8-9, 1981; locations have not been determined at this time.

The results of the elections were announced by Hodie Tannenbaum, chairperson of the Nominating Committee and are reported elsewhere in this issue.

Beverly Rollnick, newly elected president, addressed the meeting outlining her goals and plans for our Society in the coming year. The transcript of her address is included in this issue.

The meeting was adjourned and was followed by an informal reception.

OPENING REMARKS, continued

Speakers and workshops were selected to take full advantage of the wide range of professional resource people within our ranks as well as from allied health professions, including people with expertise in the fields of social work, public health, nursing and psychiatry.

I had the privilege to attend the Region VI meeting in California in July, 1980. The sentiment of the participants exceeded enthusiasm and approached exuberation. The response was related to the recognition of common bonds in terms of interests, problems and purposes as well as pride in the quality of work demonstrated by the papers presented and the discussions. The participants recognized the value of meeting together in small groups with colleagues with whom they would otherwise have had no contact. I have been told that each and every regional meeting has produced similar response.

Each regional meeting also included a business meeting for discussion of regional and national plans and goals. The Regional Representatives will present the results of these meetings at the Board of Directors meeting so that the main thrust of these regional discussions can be incorporated into program and policy planning for the future. The Regional Representatives also communicate the outcome of the Board Meetings to their constituents via Perspectives, by written communication or at subsequent regional and local meetings. This is the structure of the National Society of Genetic Counselors. Each of you has access and input to the Board of Directors through your Regional Representative, by direct communication by mail or at the annual business meeting.

The Society has no identity of its own. As a professional society it is intended to represent those professionals who are its members. The Board of Directors should be representative of the common interests of the members. Each of you should participate constructively as a committee member and by attendance at local, regional and national meetings. Some of you will go on to become members of the Board of Directors. The Society will always reflect the input of active members who, I would hope, recognize their responsibilities to all members and the profession as a whole. I cannot emphasize this point enough. When considering purposes and program for the National Society of Genetic Counselors it is essential to have a broad national view of the genetic counseling profession and a long range view of professional goals. Those of you who are new to the profession will find that being a member of this professional society will help you to appreciate these long term goals.

Our members include genetic counselors who have come into the profession with a variety of post-baccalaureate degrees including those in nursing, social work, public health, basic genetics and genetic counseling. The important factor, it seems to me, is the professional orientation that brings us together. It makes little difference that our titles are not all the same or that some of us work in administration, education or research in clinical genetics. What is important is that all of us are trained to do genetic counseling either academically or on the job and therefore have more common interests than differences. It is these common interests that the National Society of Genetic Counselors is designed and determined to serve. The variety of backgrounds within our ranks could become our greatest asset - we have so much to learn from one another.

As I conclude my term of office as the first President of the National Society of Genetic Counselors, I feel that my primary goal has been realized. We have a professional society, national - not only because the title so designates, but authentically because we are working together on a nationwide basis with bonds formed by common professional interests as well as by friendships that would otherwise never have had the opportunity to develop.

The professional potential of this society is enormous. Let us continue to work together in the spirit of cooperation and common purposes to realize the promise of the National Society of Genetic Counselors.

I thank you most sincerely for the opportunity and the privilege to have served as President of the National Society of Genetic Counselors during the first, formative years. Thank you, also, to the Board of Directors for their outstanding support and cooperation. And to all of you, my appreciation for joining in the efforts to establish this Society. I look forward to many years of fruitful collaboration.
WHY A NATIONAL SOCIETY OF GENETIC COUNSELORS?
Beverly R. Rolnick, M.S., Ph.D.

Thank you for your expression of confidence by electing me to serve as President of the National Society of Genetic Counselors. In its brief lifetime our Society has made many remarkable achievements in which we can all take pride. They have been accomplished by talented, dedicated and very hard working colleagues. Many of them are ending their terms of office. Others are assuming new responsibilities. To each we owe our appreciation and gratitude for jobs very well done.

In particular, our outgoing President, Audrey Heimler, provided the strong, statesmanlike leadership essential for the successful beginning of an organization. I hope to follow her outstanding example during the coming year.

This meeting, with our first elected slate of officers, is an important occasion for all of us. I have undertaken a presidential address with some trepidation. In the case of a new organization, there is a responsibility to enunciate its aspirations. How does one begin? Perhaps it might be useful to begin by asking some obvious questions. Why do we need a National Society of Genetic Counselors? Who are we? What are our objectives? A review of the context in which genetic counseling is evolving provides a framework for a more comprehensive response to these questions and illustrates the current challenges we face.

I will address three major areas that have relevance to our profession:

1) the pattern of growth in genetic counseling services;
2) the pattern of service delivery; and
3) the funding of services.

The first modern day genetic counselors were MD’s or PhD’s with or without training in human genetics and/or counseling skills. The magnitude of health care needs in human genetics created by the increasing number of diseases with a recognized genetic component, and rapid medical advances and their application to early identification and possible prevention, provided the impetus for new approach. The late Dr. Melissa Richter, a Dean at Sarah Lawrence College, provided the answer. She foresaw that the genetic revolution would require specialized professional skills to meet what she perceived would be the growing public demand for genetic services. Dr. Richter reasoned that individuals could be trained at the masters degree level in human genetics and counseling skills and could work with medical geneticists sharing responsibility as members of a clinical genetics team.

Statistics reflect the changing composition of the ranks of genetic counselors. In Sorenson’s 1973 survey of the United States, 650 individuals responded that they did genetic counseling on a regular basis. Seventy three percent were physicians; 11% were masters degree or RN genetic counselors. Only 7 years later, in 1980, the genetic counseling training programs had graduated over 300 individuals, of whom two-thirds are employed as genetic counselors. Others are employed as educators, researchers, or administrators. I know of no comparable statistics on the number of genetic counselors from related disciplines, but it is substantial.

The change in the composition of the ranks of genetic counselors has been accompanied by growth in availability of genetic counseling services. The number of centers in the United States providing genetic counseling services grew from 10 in 1951 to 267 in 1977. Genetic counseling ranked second among the most frequently provided genetic services. International growth of genetic counseling has followed pace.

Despite this expansion, the impression persists that the need and demand for genetic counseling far exceeds the supply of genetic counselors. The changing pattern of service delivery is both beginning to narrow this gap, and also making it more apparent. Initially, the majority of genetic services were provided at university medical centers, often as an integral part of a research protocol. Therefore, the number of patients served was small. Rapid advances in human genetics have moved genetics service programs further and further from a research base. Genetic knowledge and technology is now being applied to large populations and is considered to be part of public health.

This pattern reflects a shift in the attitude of at least some government health policymakers. Historically they had linked eugenics and genetics, and refused to legislate in either area. Today, many genetic outreach programs function under the auspices of the federal or state government. Many government programs require by statute provision of genetic counseling in conjunction with testing and diagnosis. These trends, which are likely to continue, have resulted in government having an interest in the training, continuing education and professional standards of genetic counselors. We must have a measured response to this interest.

As genetic services move from a research base and become part of more routine health care, several consequences can be predicted. First, the short term demand for trained personnel can be expected to remain high. Second, for-profit-only facilities for amniocentesis, chromosome analysis and other genetic services may proliferate. Provision of genetic services in more traditional public health and medical settings will increase their availability. This is desirable. However, increased access to genetic counseling and other genetic services must not be at the expense of decreased quality. We welcome the new professional opportunities offered by changing service delivery patterns. But we must be vigilant in insuring continued high professional standards and proper medical supervision in these new settings.

The shift of genetic services away from a research base also raises the critical question of funding. We all know that money makes the world go around. The funding of genetic services is at a turning point, and genetic counselors will feel the impact. A major portion of the cost of genetic evaluation and counseling has been paid for by federal research grants. This pattern cannot continue. Federal research dollars have remained relatively static at a time of rising demand. Simultaneously, the (continued on p. 4)
March of Dimes - Birth Defects Foundation, a long time source of support for genetic services, is developing a new program focus.

Part of the dollar gap has been taken up by government service programs. Appropriations from the National Genetics Disease Act are supporting wholly or in part many state and regional genetic service and education programs, including newborn and metabolic disease screening programs. The Division of Services to Crippled Children pays for genetic services in some circumstances, but their pattern is inconsistent, even within the same city. Government financial support is important, and to be encouraged. However, it cannot fully meet the demand. This government pot is not deep, and it does have a bottom.

The message is clear. The pattern of no fee for genetic services must be changed. Genetic services must pay their own way. Financing will have to come from the private sector: third party payers. Some progress has been made. An unknown but growing number of private insurance companies will reimburse physicians for genetic services rendered, but generally not genetic counselors. The largest third party payer, Blue Cross-Blue Shield (BCBS), has no national policy on coverage for genetic services. This issue was addressed at the 1979 Asilomar conference on genetic counselors. One result is that BCBS, with funding from the March of Dimes - Birth Defects Foundation, has undertaken a national needs assessment. The hoped for outcome is that BCBS will recommend coverage for genetic services to its member groups. However, BCBS policy requires that payment go to physicians. Lack of direct reimbursement may present a potential problem to genetic counselors. There are additional potential problems. Along with other allied health professionals, genetic counseling professionals are filling the gap between demand and supply, and contributing to more productive use of physician time by freeing them for other functions. Researchers have recently predicted a coming physician glut, and advocate reduction or elimination of allied health training programs as one solution.

As genetic counseling professionals, then, we face many challenges: funding, access, service setting, professional standards and professional rights. These concerns are shared by the broader clinical genetics community. The 1970's were marked by discussions on licensing, certification, the process of genetic counseling and who should do it. When a small group of genetic counselors met in 1978 to discuss a professional organization, they were aware of the many forces in motion. These forces were affecting the professional status of large numbers of genetic counselors who were working a variety of settings across the country: genetic counselors who had no unified voice. It was time to organize. The National Society of Genetic Counselors was formed in this context to represent genetic counseling professionals.

Being a member of new profession can be a challenge. We have the opportunity to help shape the mold by fashioning the principles, standards and image of our profession. But being a member of a new profession can also be intimidating. Few have gone before us. We must define our role, establish our identity with other professionals, bargain for our salary and benefits, and design a path for professional advancement. And being a member of a new profession is a responsibility: to ourselves, to our fellow professionals, and to the families we serve. The manner in which we meet the challenges facing us will affect future generations of genetic counselors. While we had few to follow, they will follow us. We must meet the challenges and we must meet them well. But we no longer have to face the task alone. By joining together we can define our professional needs and fulfill our professional aspirations. We can take pride in the level of professionalism we have achieved. But this pride must not blind us to the unmet challenges.

Some of these challenges are clearly before us. Others remain to be identified and addressed. Several will provide the focus of my year in office as President of the National Society of Genetic Counselors.

First, we have a professional interest in and obligation to contribute to the definition and maintenance of standards in genetic counseling. Our Society can participate by:

1) continuing to sponsor national and regional education meetings; a national education meeting is currently being planned;
2) by ongoing professional involvement in the certification process;
3) by working with appropriate groups to implement the recommendations of the Asilomar conference on the training, continuing education, professional standards and funding of genetic counselors.

Second, our professional status is enhanced by the quality of our professional contributions. Our Society can plan and implement national professional projects. Plans are currently underway for:

1) a national assessment of how priorities are established for genetic counseling services, under the auspices of the Social Issues Committee; and
2) an international meeting or: pedigree standardization, under the auspices of the Professional Issues Committee.
3) I propose a survey of third party payers to assess reimbursement policies for genetic services.

Third, professional communication is a major mechanism for keeping informed. Perspectives in Genetic Counseling will expand its editorial board and add relevant information not provided elsewhere on a systematic basis.

Fourth, professional growth and advancement is a legitimate aspiration. To design avenues for professional advancement we first must learn who we are and what (continued on p. 5)
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BUSINESS MEETING, continued

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PRESIDENTS ADDRESS, continued

we are doing. An ad hoc committee will be appointed to survey the professional status of our national member-
ship. The data will provide the basis to develop strategies for involvement.

Fifth, an active and substantial membership will strengthen the voice of our society and enhance our abil-
ity to achieve our goals. Our efforts to expand our membership will continue.

To insure the success of these projects efforts will be made to obtain funding from a variety of sources.

I pledge my support of these activities. I am sure I can speak for the members of the board in pledging their efforts as well. But more is required. The National Society of Genetic Counselors exists to serve the goals of its members. But the relationship is symbiotic. You, our members, are the lifeblood of the society. Your support and your participation are essential.

At the beginning of my remarks, I asked three questions. Who are we? Why do we need a National Society of Genetic Counselors? I have attempted to for-

ge answers to these questions and to identify some challenges. The future is before us. The prospect is ex-
hilarating. Let us choose the way it will happen!

NEWLY APPOINTED COMMITTEE CHAIRS AND REGIONAL REPRESENTATIVE

Several vacant positions on the Board of Directors were filled due to resignation or election to another board position.

Roberta Spirito, Co-Chair, Education Committee, has resigned for personal reasons. Judith Dichter, Co-
Chair, of the Education Committee, has been elected as Region II Representative. Evelyn Lillienthal, Membership Chair, has ended her term of office. Ann Smith, who has served as Region V Representative, has been elected as President Elect. I would like to thank these individuals for their contributions to the Society in these capacities.

I have appointed the following members to fill these positions, and the board of directors has voted approval.

Education: Susan Reed, Seattle, WA
Membership: Hody Tannenbaum, New York, NY
Region V
Representative: Joan Scott, Denver, CO.

In addition, I have established two ad hoc commi-
nites.

1. Ad hoc Committee on Professional Status, Michael Begerle, Chair. This committee will be responsible for surveying the professional status of our membership. Data will be used to help establish guidelines and an NSGC policy state-
ment for professional status.

Several regions have initiated pilot surveys that requested similar information. We will appreci-
ate your cooperation in responding to this ques-
tional, which will standardize this information on a national basis.

INSTRUCTIONS FOR CONTRIBUTORS TO PERSPECTIVES IN GENETIC COUNSELING

TYPES OF CONTRIBUTIONS ACCEPTED

Authors may submit for consideration of publica-
tion: articles dealing with the varied professional roles of the genetic counselor, single case reports with discus-
sion of difficult areas of management and prospective means to improve the provision of genetic services, or letters to the editor which deal with issues relevant to the profession of genetic counseling or to the Society.

INSTRUCTIONS

All contributions must be typed, double spaced. Three copies of each article should be submitted. The author’s name, preferred title and address must be included with all contributions. To be considered for pub-
lication, the contributions must not exceed 2000 words or 10 double spaced pages. Articles and letters must be received by no later than the first day of the month preceding the month of publication (i.e., the deadline for the December issue is November 1).

SEND ALL CONTRIBUTIONS TO:
Deborah E. Eurelings,
Perspectives in Genetic Counseling
Clinical Genetics Center
Children’s Hospital of Philadelphia
Philadelphia, Pennsylvania 19104

2) Ad hoc Committee, National/Regional Educa-
tion Units. Donna Goodwin, Chair. This com-
mitee is charged with development of national education components to be included in re-
gional education meetings.

I have appointed Sylvia Rubin to serve as Archivist for the NSGC. Sylvia has been compiling the important documents of the NSGC. These papers, accumulated since the inception of the NSGC will provide an impor-
tant historical record.

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lication, the contributions must not exceed 2000 words or 10 double spaced pages. Articles and letters must be received by no later than the first day of the month preceding the month of publication (i.e., the deadline for the December issue is November 1).

SEND ALL CONTRIBUTIONS TO:
Deborah E. Eurelings,
Perspectives in Genetic Counseling
Clinical Genetics Center
Children’s Hospital of Philadelphia
Philadelphia, Pennsylvania 19104

2) Ad hoc Committee, National/Regional Educa-
tion Units. Donna Goodwin, Chair. This com-
mitee is charged with development of national education components to be included in re-
gional education meetings.

I have appointed Sylvia Rubin to serve as Archivist for the NSGC. Sylvia has been compiling the important documents of the NSGC. These papers, accumulated since the inception of the NSGC will provide an impor-
tant historical record.

INSTRUCTIONS FOR CONTRIBUTORS TO PERSPECTIVES IN GENETIC COUNSELING

TYPES OF CONTRIBUTIONS ACCEPTED

Authors may submit for consideration of publica-
tion: articles dealing with the varied professional roles of the genetic counselor, single case reports with discus-
sion of difficult areas of management and prospective means to improve the provision of genetic services, or letters to the editor which deal with issues relevant to the profession of genetic counseling or to the Society.

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REPORT FROM THE NOMINATING COMMITTEE

Results of the first election of the NSGC are as follows: President, Beverly Rolnick; President-Elect, Ann Smith; Secretary, Virginia Corson; Regional Representative II, Judith Dichter; Regional Representative IV, Monica Wohlfert; Regional Representative VI, Richard Apostol. Congratulations to our new slate of officers and many thanks to all the candidates who were willing to serve.

A total of 198 ballots were mailed out; 55% of the members responded: 10 out of 15 members responded from Region I; 47 from 96 in II; 5 from 8 in III; 16 from 21 in VI, 10 from 20 in IV; and 21 from 36 in VI.

No response we received from two members in Israel.

Next year's Nominating Committee is: Diane Baker, Audrey Heimler, Evelyn Lilienthal, Lucille Poskanzer and Julie Shapiro. We will be voting for President-Elect, Treasurer, Regional Representatives from Regions I, III, and V. The new Nominating Committee is anxious to hear from the membership and looks forward to your suggestions and recommendations.

Members of the Nominating Committee can be reached as follows:

Diane Baker - 309 North Ingalls, Apt. 1, Ann Arbor, MI 48104
Audrey Heimler - 15 Geoffrey Lane, Hewlett, NY 11537
Evelyn Lilienthal - 34 Duncan Drive, Greenwich, CT 06830
Lucille Poskanzer - Children's Hospital 51st & Grove St., Oakland, CA 94609
Julie Shapiro - 3706 N. Charles St., Apt. 3-D, Baltimore, MD 21218

POSITIONS AVAILABLE

Genetic Associate
The Massachusetts Department of Public Health is anticipating the receipt of federal funds for a state-wide program of genetic services. Positions for genetic associates and a social worker may become available October, 1980, or shortly thereafter. Contact: Yale Bohn, Genetics Program, State Laboratory Institute, 305 South Street, Jamaica Plain, MA 02130, telephone (617) 522-3700 ext. 108.

Two Genetic Counseling Positions
Full-time opening for a person with masters level training as Genetic Associate or Equivalent, to work in a university-based Regional Genetic Counseling Program. Clinic coordinator for Prenatal Genetic Clinic. Clinical, teaching, and administrative responsibilities. Position opens September 1, 1980. Competitive salary.

Half-time Genetic Associate position also available for a person with same training and also to work in the Prenatal Genetic Counseling Clinic with responsibilities for genetic counseling, teaching, and supervision. Position open September 1, 1980, or later. Competitive Salary.

Send resume to:
Philip D. Buchanan, Ph.D.
Genetic Counseling Program
Department of Pediatrics
University of North Carolina
Chapel Hill, NC 27514
Or call: (919) 966-1447
An Affirmative Action Equal Opportunity Employer.

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