

## **An Oral History of the National Society of Genetic Counselors**

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*Master's level genetic counselors formed a professional society in 1979, 8 years after the first master's degree training program graduation. This paper presents an oral history of the early years of the National Society of Genetic Counselors (NSGC), reviews the symbiotic development and definition of a profession and a professional society, and discusses events and achievements attributed to the NSGC since its incorporation. This retrospective historical account is based on personal and collective oral history, NSGC archival material and other sources.*

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**KEY WORDS:** professional organizations; genetics; history; founding a professional society; professional self-determination; genetic counselor.

### **INTRODUCTION**

This paper, based on a lecture given at the Annual Education Conference of the National Society of Genetic Counselors in Montreal, Canada, October 15, 1994 examines the contribution of the National Society of Genetic Counselors (NSGC) to the evolution of the genetic counseling profession from the perspective of master's degree level genetic counselors. The narration begins with a personal account of early NSGC history and concludes with a discussion of events and achievements to illustrate important professional milestones. This retrospective historical account is based on personal and collective oral history, a paper by Beverly Rollnick summarizing the first 5 years of NSGC history (Rollnick, 1984), NSGC archival material, and a variety of other sources.

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### PRELUDE TO A PROFESSIONAL SOCIETY

Credit for proposing a professional society has been claimed by several individuals, and probably originated from more than one source over a period of years. For example, Gillian Ingall, one of the first genetic counselors, wrote to me as acting NSGC president, informing me that a professional genetic counseling society had been discussed as early as 1973 at the International Genetics meetings in Paris (Ingall, 1979).

By 1977, the concept of a professional society was an idea whose time had come. Joan Marks, Director of the Human Genetics Program at Sarah Lawrence College (SLC), discussed the need and benefits of a professional society with Deborah Eunpu who was about to graduate from the program and with other students enrolled in the program. The students were enthusiastic about a society and the possibility of starting a newsletter for genetic counselors. Joan Marks advised them to interest practicing genetic counselors. Deborah Eunpu contacted directors of training programs, and began to assemble a national mailing list (Eunpu, 1994; Marks, 1994).

In March 1977, Joan Marks invited several students, including Luba Djurdjinovic, Debra Timmons and Joan Scott, and Deborah Eunpu, who was by that time an alumnus, to a postgraduate seminar to meet the practicing genetic counselors who regularly attended this seminar, in order to initiate a discussion of a professional society. Joan Marks emphasized that "certification for genetic counselors was on the horizon, and genetic counselors had better organize if they were to have a voice and a vote in the process" (Marks, 1994). Lorraine Suslak, a genetic counselor present at the meeting, immediately became a proponent for the proposed society, convincing the other genetic counselors, including myself, that the time was ripe for a professional society. There was unanimous agreement to test the waters.

One month later, the SLC consortium of genetic counselors and students invited the directors, students, and alumni of the three genetic counseling programs in the New York area, Rutgers University, Stony Brook University, and SLC, to a meeting at New York Hospital. As Joan Marks recalls, "It was an emotional experience to see, for the first time, 100 genetic counselors in one room and to observe them considering the implications of unifying as a society" (Marks, 1994). I had the responsibility of chairing that meeting at which there was a heated discussion and dissenting opinions. Finally, the group agreed to seek a national consensus on a society (Heimler, 1979).

A meeting to continue discussion of a professional society was announced for June 1979 to coincide with the March of Dimes–Birth Defects Foundation (MD–BDF) meeting in San Francisco, where it was anticipated

genetic counselors from other parts of the country could join the debate. Lorraine Suslak moderated this meeting. Some genetic counselors maintained, "We're gaining ground as professionals. Let's not be too aggressive right now." Others questioned, "Will we jeopardize the stature we have attained as individuals if there is a negative response to a unified professional group?" "Will the new society be nationally representative?" "How will early leadership be decided?" Deborah Eunpu described the concern raised by a physician colleague, who asked if the NSGC would be like a union, and said this possibility was a problem for her (Eunpu, 1994).

To assure national participation in the dialogue concerning a professional society, the founding group held a third meeting to coincide with the American Society of Human Genetics (ASHG) Meeting, October 1978, in Vancouver, British Columbia. While the meetings failed to produce a mandate, I was one of a core of individuals who were determined to proceed.

## DEVELOPMENTAL MILESTONES

### By-Laws

After the April 1978 meeting in New York City, Lorraine Suslak, Niecee Singer, Sylvia Rubin, Hody Tannenbaum, Luba Djurdjinovic, Evelyn Lilienthal, Phyllis Klass, Deborah Eunpu, and I established the Committee to Form the National Society of Genetic Counselors to formulate by-laws for the proposed society. Over the next 14 months, the group met biweekly in committee members' homes or at Long Island Jewish Medical Center, New Hyde Park, NY.

Recognizing that there could be no official election until there were members, and no members until by-laws would be written, the committee proceeded to nominate and elect an *ad hoc* board of directors for the purpose of writing by-laws and designating interim responsibilities.

If the constitution of the United States of America could be written in 4 months, why did the By-Laws Committee deliberate for 14 months? Luba Djurdjinovic remembers thinking "How we do this will determine how we will be perceived. We are charged with the responsibility of defining the profession of genetic counseling and the professional who is a genetic counselor. The by-laws of the proposed society will set the tone for the profession" (Djurdjinovic, 1994). In the words of Beverly Rollnick, "The growth of the professional has paralleled the growth of the NSGC. Since both were new, the founders faced the necessity and challenge of defining and establishing each simultaneously. The process was symbiotic" (Rollnick,

1984). The By-Laws Committee progressed slowly, pondering these considerations with every decision.

Three perplexing issues faced the By-Laws Committee: the name of the society, membership criteria, and national representation.

### **The Name Becomes an Issue**

The discussion regarding the name of the society was focused on the lack of consensus over a title for the new professional: genetic associate or genetic counselor. The By-Laws Committee members knew colleagues who preferred “genetic associate” as (1) a flexible title applicable to individuals who were not primarily counselors, or (2) feared adverse reactions in their work setting to demands for a new title. The committee understood that those in favor of “genetic counselor” believed (1) it best described the training, graduate degree, and expertise of the majority of professionals the society would represent, and (2) “associate” presumed a dependent role.

Medical geneticists who considered themselves genetic counselors influenced this debate. Their viewpoint first came to my attention during the ASHG meeting in October 1972 when Charles Epstein, MD presented a paper entitled “Who should do genetic counseling and under what circumstances?” He stated, “To me, the term ‘genetic counselor’ connotes one who is capable of giving genetic counseling, with all that it entails. It is my contention, and I am prepared to be proven wrong, that except in the rarest of instances, non-medically trained individuals are not so prepared... because counseling must be based on the medical implications of an accurate diagnosis...I do not see how anyone without medical training can honestly accept responsibility in these areas.” He conceded that others, e.g., “basic geneticists (PhD), public health nurses, social workers, or genetic associates... are certainly capable of providing valuable assistance and of carrying out many of the functions that are part of the overall counseling situation...I do not regard these individuals as ‘genetic counselors’... associates, assistant, aides, collaborators, yes; counselors, no!” (Epstein, 1973).

I had entered the SLC Human Genetics Program to become a “genetic counselor,” and had been a genetic counselor for 2 years when I heard the above statement. Stunned by Dr. Epstein’s statements, I looked around the large auditorium and was dismayed that medical geneticists, some of whom had been advisors to the SLC program, failed to disagree with Dr. Epstein’s opinion. As the only genetic counselor present, a novice attending my first ASHG meeting, I confess I did not challenge Dr. Epstein, but I realized

genetic counselors would have to define, and possibly defend, their place in the medical genetics community.

Further documentation for the medical genetic communities' viewpoint on this issue can be found in *The 1973 Report of a Site Visit of the Advisory Committee to the Human Genetics Program of Sarah Lawrence College* which states, "The Board [Advisory Committee] discussed the appropriate designation of trainees of the program. It is felt that the title 'genetic counselor' was somewhat misleading in that it might indicate to hospitals, public health departments, and physicians not acquainted with medical genetics that graduates of the program would be fully trained genetic counselors. Genetic counseling services require much more than skill in counseling troubled people and acquaintance with the principles of human genetics. The considerable heterogeneity and complexity of many genetic issues requires that the genetic counselor usually be medically trained, since wrong diagnoses may lead to bad advice. Affiliation of genetic associates with a physician will not be sufficient, since most physicians lack the background unique to medical geneticists. The [SLC] program would acquire a bad reputation if its graduates were to go out and be considered 'genetic counselors'" (Bearn *et al.*, 1973).

Six years later, some members of the medical genetics community pressed the By-Laws Committee to include physician and dentist geneticists in the full membership category. As acting president, I was often locked in lengthy, acrimonious debates with physicians over this issue. Pointing to heterogeneity among clinical geneticists, they proposed a heterogeneous professional society. A society of nonphysician genetic counselors, they argued, would imply physicians were not genetic counselors and thus define genetic counselors as independent professionals. They opposed the title of "genetic counselor" for the professional and the professional society. The rebuttal argument proclaimed that self-determination for master's degree level genetic counselors would provide advantages for professional recognition, continuing education, and professional issues specific to genetic counselors.

Other events came to bear on the decision-making process of the By-Laws Committee. Three meetings, familiarly referred to as "The Asilomar Conferences," occurred between 1975 and 1979, two at California State Park Conference Grounds at Asilomar, and the third in Williamsburg, VA. At the first meeting, training program curricula were compared to needs of practicing genetic counselors. At the second meeting, sponsored by the National Foundation–March of Dimes (NF–MD), participants explored "the role of the genetics associate in the provision of genetic services and possible means of support for genetic counseling services" (University of California, Irvine, 1979; Walker, 1979) The third conference, sponsored by

The Office for Maternal and Child Health, Department of Health, Education and Welfare, provided a forum “for agencies and organizations increasingly involved in the provision of genetic services to consider the goals of training and the role of the genetic associate in the provision of genetic services” (University of California, Irvine, 1979; Walker, 1979). Among the 50 participants were 11 graduates of genetic counselor training programs and 39 others, including directors of training programs, medical geneticists, and representatives of governmental agencies. During the third meeting, physician participants initiated an unscheduled, lengthy, heated debate regarding a title for the new professional. Should the title be “genetic associate” or “genetic counselor?” Surprised by this discussion, genetic counselors refused to concede the title. When there seemed to be no way to resolve the issue, Linda Lustig seated with Charles Epstein, who was then the chairperson of her department at the University of California, Berkeley, proposed, with amusement, a compromise: the “designation ‘genetics associate’ for students in an established training programs; the title ‘genetics counselor’ for those providing the service” (Lustig, 1994). Exhausted physicians and genetic counselors, otherwise at an impasse, affirmed the compromise by a show of hands. Although there was no mandate at this meeting to address or decide this issue, the decision proved critical. Genetic counselors who were not present at this meeting were unaware they could have been stripped of their title, and may not have recognized the significance of the following statement in the report of the meeting, “Efforts should be made to secure general acceptance of the job classification ‘genetics counselor’ by relevant governmental agencies, hospitals, clinics, and other providers of health services” (Mertens *et al.*, 1986; University of California, Irvine, 1979; Walker, 1979).

To the consternation of genetic counselor participants at the same meeting, the physicians initiated another discussion, again without mandate, of the plans to form a national professional society. Physicians spoke angrily of being excluded from full membership. Joan Weiss recalls that genetic counselors were “put on the defensive” (Weiss, 1994). The counselors made no concessions, and left the meeting sobered by the opposition to the proposed society within the medical genetics community.

With some trepidation, given the above history, the By-Laws Committee decided in favor of what they viewed as the strongest position: graduates of master’s degree training programs were equipped to provide genetic counseling, and should be called “genetic counselors.” They believed that any other title would diminish the definition of the profession. Accordingly, the professional society would be “The National Society of Genetic Counselors” (Heimler, 1979).

### MEMBERSHIP CRITERIA

The By-Laws Committee set out to determine eligibility criteria and membership categories for genetic counselors, as well as physicians, dentists, nurses, social workers, and allied health professionals who were providers of genetic counseling services. Anticipating board certification, it would have been easy for the By-Laws Committee to decide that criteria for full NSGC membership would conform to board certification in genetic counseling. By doing so, however, decisions about the definition of a genetic counselor would have been relegated to a heterogeneous group, The Board of Directors of the proposed American Board of Medical Genetics (ABMG). The Committee therefore determined to establish criteria for full membership for genetic counselors, intending that this standard would influence the pending certification process.

In 1979, there were medical and dental geneticists who were respected providers of genetic counseling some of whom taught and mentored genetic counselors. Nevertheless, the overriding consideration of the By-Laws Committee was the need for a homogeneous, autonomous, professional society. Although genetic counselors might work as partners with medical geneticists, the proposed professional society needed to be structured to promote professional interests, stimulate professional communication, and provide continuing education specific to genetic counselors. The committee believed the future of the profession depended on separate professional identification for genetic counselors.

Equally complicated was the decision concerning nurses, social workers, and other allied health professionals working in genetic counseling settings with whom genetic counselors felt a professional bond. In 1978, several nurses and social workers had genetic counseling experience that predated master's degree genetic counseling training programs. In addition, the members of the By-Laws Committee anticipated valuable contributions in counseling for genetic disease from future professionals in these disciplines.

Members of the By-Laws Committee and representatives of these professions discussed the role of colleagues from allied professions. I remember a conversation with Elizabeth J. Thomson, RN, MS, during the NF-MD meeting in Chicago, June 1979. Speaking for nurses working in genetics, she proposed "full membership status for registered nurses and those with master's degrees in other fields, whose knowledge of genetic disorders and counseling was acquired during training and/or in job settings" (Thomson, 1994). Sincere efforts were made to assure Elizabeth Thomson and others that qualified professionals from nursing and other disciplines would be valued as members of the proposed society.

Joan Weiss, MSW, speaking for social workers believes that “most social workers in genetic counseling settings, unlike nurses, have little or no background in science and medicine.” When the NSGC was forming, she remembers that “social workers perceived their primary identification to be in their own profession and professional society. Those who wished to join the new society were comfortable with associate membership.” Since 1979, she has believed that “associate membership in NSGC is appropriate for social workers who are involved with genetic disease” (Weiss, 1994).

The By-Laws Committee carefully considered all of the above discussions and issues regarding full membership criteria, and was mindful of a statement in the report of the third Asilomar Conference detailing specific curriculum requirements for the training of genetic counselor: a 2-year genetic counseling program leading to a master’s degree (University of California, Irvine, 1979).

Eventually, membership criteria were established in three categories: (1) “Full Membership: For persons with a master’s or PhD degree in human genetics from a recognized genetic counseling training program or in a related field, e.g., nursing, social work, or public health and whose primary responsibility for at least 3 years prior to membership application has been genetic counseling encompassing a broad range of genetic disorders. A grandfather clause established a 1-year period of membership eligibility (extended to 2-years by the NSGC Board of Directors by amendment to the By-Laws, October 1980) for persons with a baccalaureate degree in any field who has genetic counseling experience as described above. (2) Associate Membership: For those who do not desire or qualify for full or student membership although their interests focus on genetic counseling, e.g., physicians, dentists, social workers, or nurses. Associate members may not vote, hold office, or serve on the Board of Directors or NSGC committees. (3) Student Membership: For *bona fide* students in a college or master’s degree program. Students member’s have all the privileges of associate membership” (NSGC, 1979a).

Many nurses, social workers, and allied health professionals have been active, dedicated NSGC members, one of whom, Ann Brown, RN, MPH, was elected to the ABMG, Board of Directors in 1985 as a genetic counselor.

#### NATIONAL REPRESENTATION WITHIN THE SOCIETY

The third and final issue faced by the By-Laws Committee was the need to establish a mechanism for a nationally representative society. Prospective members were concerned that a disproportionate number of foun-



ders were from Eastern United States (Rubin, 1979b). The By-Laws Committee determined to move quickly to eliminate this condition.

The By-Laws Committee designated six geographic regions, selecting Department of Health, Education and Welfare (DHEW) boundaries to facilitate coordination with pre-existing regional genetics programs and criteria for DHEW funding (Suslak, 1979). Each NSGC region would have a representative who would serve on the NSGC Board of Directors. The regional representatives would be responsible for organizing members in their region, providing continuing education by holding a regional educational meeting at least once per year, communicating members concerns to the Board, carrying to their constituency the mandate of the proposed society, and developing new leaders. The regional representatives understood that their grass roots responsibilities were essential to the acceptance of the national society (Rubin, 1979b). The Committee immediately sought candidates for these positions. Once representatives were appointed, the *ad hoc* Board of Directors was complete (Table I). With the hope that their decisions would not precipitate a premature demise of the proposed society, the *ad hoc* Board of Directors approved the By-Laws in June 1979 and submitted the document to Barry Dichter, the attorney hired by the Committee to Form a National Society of Genetic Counselors.

**Table I.** The *ad hoc* Board of Directors of the Committee to Form the National Society of Genetic Counselors

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Elected:	
President	Audrey Heimler
Vice President	Lorraine Suslak
Secretary	Sylvia P. Rubin
Treasurer	Niecee Singer
<i>Appointed Committee Chairs:</i>	
By-Laws Committee	Hody Tannenbaum
Education Committee	Judith Dichter and Roberta Spiro
Membership Committee	Evelyn Lilienthal
Professional Issues Committee	Phyliss Klass
Social Issues Committee	Ann P. Walker
<i>Appointed Regional Representatives:</i>	
Region I	Stacey Kacoyanis
Region II	Virginia Corson
Region III	Debra Timmons
Region IV	Beverly R. Rollnick
Region V	Ann C. M. Smith
Region VI	Carolyn Bay
Appointed Editor, Newsletter:	Deborah L. Eunpu

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### **The Regional System Becomes a Reality**

In 1979, the first regional meetings were held in Regions I, III, IV, V, and VI (Rubin, 1979b). Achievements of Region VI Representative, Carolyn Bay, illustrate the immediate success of the regional representative system. Carolyn Bay recalls receiving my letter in early 1979 inviting her to serve as Region VI Representative for the fledgling NSGC. Her response was a scribbled message, "Very busy. Happy to help. Let me know what I can do" (Bay, 1994). I asked her to "organize the genetic counselors in Region VI, and to hold a regional educational conference." She knew four Region VI genetic counselors: three had met at a meeting in 1976 in Vancouver: Susan Reed from Seattle, Cindy Dolan from Spokane, Bill Herbert from Los Angeles and Linda Lustig, her classmate from the University of California at the Berkeley training program in San Francisco. She asked them to organize the genetic counselors in their areas and get them to come to a NSGC regional education conference at Berkeley on May 19 and 20, 1979. She applied and received a \$500 grant from the California chapter of the NF-MD. Using \$125 for food, she was able to pay each speaker an honorarium of \$7.50 and divide the remainder among participants to subsidize transportation costs. Each of the 57 participants successfully obtained the balance of their expenses from their departments (Rubin, 1979b; Bay, 1994).

The March of Dimes-Birth Defects Foundation (MD-BDF), impressed by the educational potential, agreed to provide \$1500 for the Second Region VI Meeting attended by 130 members, July 25 and 26, 1980 at Stanford University. This early connection with the MD-BDF resulted in their funding several national NSGC educational meetings.

I was invited to the Second Region VI Meeting as NSGC president and spoke on the topic chosen by Carolyn Bay, "The Art of Genetic Counseling." I recall my excitement and gratification to see the concept of the national society unfold as Region VI genetic counselors met, networked, exchanged experiences, and shared educational material (Heimler, 1980a).

### **SUMMARY OF ACHIEVEMENTS OF THE COMMITTEE TO FORM THE NSGC**

The founders, bolstered by enthusiastic support nationwide, made impressive progress during the 18 months between inception and incorporation (Table II). Two hundred and twenty-seven genetic counselors had donated \$10.00 to support the Committee to Form a National Society of Genetic Counselors. The Society had been incorporated on October 1, 1979

Table II. Historical Highlights of the National Society of Genetic Counselors

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1973	Genetic counselors discuss a professional society at the International Genetics Meeting in Paris.
1977	Graduated and students at Sarah Lawrence College (SLC) confer with Joan Marks about a professional society.
1978	Joan Marks convenes a meeting attended by students and alumni in March at SLC to discuss forming a professional society. SLC alumni convene a meeting in April in New York City, at which directors, students, and alumni of three genetic counseling training programs discuss a professional society. In April, The Committee to Form the National Society of Genetic Counselors (The Committee) is formed by a group of SLC alumni to formulate by-laws for the proposed society. An <i>ad hoc</i> board of directors is elected by The Committee and a <i>By-Laws Committee</i> is appointed. The Committee sponsors nationally representative meetings: in June, in San Francisco and in October, in Vancouver to discuss a professional society.
1979	A meeting in April in Williamsburg, VA, sponsored by the U.S. Department of Health, Education and Welfare: entitled "Genetic Associates Their Training, Role and Function," erupts into a discussion of an appropriate title for master's degree "genetic counselors" and the legitimacy of excluding medical geneticists from full membership in the proposed professional society. In March, The Committee publishes the first newsletter for genetic counselors. The second issue entitled <i>A Newsletter of the National Society of Genetic Counselors</i> is published in June. In June, the <i>By-Laws Committee</i> endorses the title of "genetic counselor," names the society "The National Society of Genetic Counselors" (NSGC), sets membership criteria for other professionals providing genetic counseling services, establishes the regional representative system, and completes the <i>By-Laws</i> . The first educational presentation takes place in Chicago, IL, June 24. Regional meetings are scheduled in five of the six "districts." The <i>Newsletter</i> , renamed <i>Perspectives in Genetic Counseling</i> , <i>The Newsletter of the National Society of Genetic Counselors</i> with the new NSGC logo, is published in September. The <i>By-Laws</i> are filed in New York State on September 28, and on October 1, the Society is incorporated in New York State. During the American Society of Human Genetics Meeting (ASHG) in Minneapolis, MN, the first NSGC Business and Board of Directors meetings are held on October 3 and 4. An NSGC representative, Phyllis Klass, is appointed to the ASHG Council on Accreditation. 1980.
1980	Two genetic counselors, Audrey Heimler and Ann C. M. Smith, are elected to the Board of Directors of the American Board of Medical Genetics (ABMG). The NSGC publishes a brochure.
1981	The newsletter becomes <i>Perspectives in Genetic Counseling</i> , with a logo, in Vol. 3(1). An NSGC computerized membership directory is published. A full-day "Education Conference" is held June 18 and 19 in San Diego, CA. A Professional Status Survey is published in <i>Perspectives</i> , Vol. 3(4).
1983	The NSGC adopts a definition of a genetic counselor's role published in the second NSGC brochure.
1984	For the first time, the proceedings of an annual educational conference are published.
1985	An NSGC contingent joins the march to support pro-choice in Washington, DC. The NSGC president, Luba Djurdjinovic, appoints an executive director.
1987	The <i>ad hoc</i> Committee on The Expanded Roles of Genetic Counselors submits the results of their study.

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Table II. Continued

1990	The NSGC establishes the Special Projects Fund and Award.
1991	The Jane Engelberg Memorial Fellowship becomes an annual NSGC award. A code of Ethics is submitted by an <i>ad hoc</i> subcommittee and adopted by NSGC. The Executive Director, Bea Leopold, convenes a council of NSGC past-presidents to develop vision and mission statements.
1992	The NSGC has a leadership role in determining the future for genetic counselors during the American Board of Medical Genetics (ABMG) "restructuring" process. <i>The Journal of Genetic Counseling</i> is published.
1993	The American Board of Genetic Counseling (ABGC) is incorporated. Genetic counselors write the genetic counseling certification examination. Directors of genetic counseling training programs must be ABMG or ABGC certified genetic counselors (allowing for "grandfathering" of current directors). The ABGC will have responsibility for accreditation of training programs.

as a not-for-profit organization in the State of New York. An application had been filed for tax-exempt status. By-Laws had been rewritten in legal language by Mr. Dichter, approved by the Board, ratified by Mr. Dichter in his capacity as sole incorporator, and filed in the State of New York September 28, 1979 (New York State, 1979; NSGC, 1979a). The first regional educational meetings had been held, and the first business meeting of the National Society of Genetic Counselors, Inc. was scheduled for October 3, 1979 during the ASHG meeting in Minneapolis. The *ad hoc* Board of Directors was pleased with the accomplishments to be reported at that meeting. This meeting should have been a celebration. There was, however, one serious concern.

The Board had been alerted about physicians who were contemplating action against the Society for the following reasons: (1) medical geneticists were excluded from full membership, (2) genetic counselors were defined as individuals trained on the master's level, and (3) genetic counselors had set themselves apart professionally from physicians who perceived genetic counselors in a dependent role. Possible outcomes included confrontation at the pending NSGC Business Meeting, legal action, and, worst-case scenario, demise of the fledgling society.

Concerned about personal and collective liability for a society with limited assets, the Board voted to bring Mr. Dichter to Minneapolis for the meeting. With assets of \$2127.68, this was a costly decision. After paying Mr. Dichter's expenses and other bills, the Society's assets were \$772.68.

The night before the meeting, the Board met with Mr. Dichter for a strategy session. It was decided that Board members would present brief reports and avoid discussion. The Board members hoped to have an intact Society when the meeting adjourned. Several board members, hoping to

deflect interference during the business meeting, talked with physicians who were identified as potential initiators of negative action. For example, 30 minutes before the meeting, Beverly Rollnick and I were embroiled in a discussion with one physician concerning the rationale for self-determination in a professional society of genetic counselors.

Mr. Dichter was seated with the Board of Directors and introduced as the attorney for the Society. About 100 members and other interested genetic counselors were seated facing the Board. Unobserved by most of the audience, but visible to the Board, were about 20 grim-faced physicians standing in the rear of the room. The meeting proceeded as planned. The Board believed that genetic counselors would have a mandate to guide their own future if the plans for the proposed society were intact at the conclusion of the meeting. The report of each board member emphasized goals of the society most likely to deflect anticipated objections. There was no discussion from the audience. This unusual meeting lasted 1 hour after which the physicians exited without comment. Board members felt relief, but no elation. There was a sense of having won a battle that should never have been fought. The cost of survival was high. At the first public business meeting, the *ad hoc* Board had been compelled to project the impression that it did not value communication among members.

Following this meeting, I received a thoughtful letter from Gillian Ingall stating that while she supported efforts to establish a professional society, she was disturbed that there had been no forum for discussion at the recent business meeting. She suggested that the Board consider a more open format for future business meetings! (Ingall, 1979). This appraisal of the business meeting was probably shared by members unaware of the tensions the Board had not wished to make public. In *Perspectives* Vol. 2, No. 3, the announcement of the Annual Business Meeting the following year includes an implied apology and acknowledgment: "The theme of this year's business meeting is 'Discussion'" (Heimler, 1980b). From that time to the present, communication among members has been an NSGC priority.

### **The First Annual Board of Directors Meeting**

The first official Annual Board of Directors Meeting of the NSGC was held the following day, October 4, 1979. (There had been two meetings of the *ad hoc* Board of Directors prior to incorporation.) Plans were in progress for the first open election in 1980 (Rubin, 1979c).

## THE NSGC FULFILLS ITS MANDATE

The NSGC emerged from this formative period with a mandate to fulfill the expectations of the founding genetic counselors and the membership who joined the effort. There was a sense of excitement, purpose, and responsibility. The future beckoned, and the torch was poised to be passed to leaders coming up through the ranks. Efforts could now be directed toward advancing the profession.

### NSGC Publications

In March 1979, the first issue of *A Newsletter of the National Society of Genetic Counselors* was published with Deborah Eunpu as Editor, and four modest pages bearing neither a heading or date. In June 1979, Vol. 1, No. 2 carried a more confident title: *Perspectives in Genetic Counseling, A Newsletter of the National Society of Genetic Counselors*. Volume 2 displays the NSGC logo, designed by Beverly Rollnick, as it appears on current NSGC letterhead. In 1981, Vol. 3, No. 1 appeared with a new title, *Perspectives in Genetic Counseling*, sporting yet another logo. The current design was introduced in 1993, Vol. 15, No. 1. The size of *Perspectives* increased over the years with recent issues having 16 pages.

Joseph McInerney, was appointed Assistant Editor in 1980 and Editor in 1984, serving until 1991 when Vicki Venne became Editor. From 1980 to 1982, partial support for *Perspectives* was provided by a grant from the MD-BDF.

In Joseph McInerney's words, "The progress of the Society was reflected in *Perspectives* in several ways. First, and most obviously, we had to print more copies each year as the membership increased. Second, the number of 'position available' announcements we carried increased as well, and it was clear that the positions were becoming more substantive. Third, the writing began to improve. Last, but most important, the quality of the articles improved as our members took hold in the community and began to deal with issues of extraordinary substance and importance. For me, this was nowhere more evident than in the section we introduced on case studies, where members presented difficult (or just interesting) cases for review and reflection. The cases generated correspondence that reflected the growing maturity of the society and the caliber of its members" (McInerney, 1994).

In March 1992, a longstanding dream became a reality when the first issue of the *Journal of Genetic Counseling* was published with Deborah

Eunpu as Editor. The new journal would focus on clinical, educational, ethical, legal, and social topics relevant to genetic counseling.

### **Early Evidence of Professional Recognition**

In the first newsletter, Phyllis Klass, Chairperson of the newly formed Professional Issues Committee, reported that the ASHG had “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 taskforces 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” (Klass, 1979). Phyllis Klass’ letter to the Council regarding representation was politely refused. A second, stronger request was eventually granted, and Phyllis Klass was invited to represent genetic counselors on the genetic counselor taskforce (Klass, 1979). She believes the recently formed professional society was an important factor in that acceptance (Klass, 1994).

As a direct outgrowth of this accomplishment, genetic counselors were granted two representatives on the Board of Directors of the ABMG in 1980, Ann Smith, and myself. During this term of office, criteria for ABMG certification eligibility were written, satisfactorily resolving the issue, “Who is a genetic counselor?” In Ann Smith’s words, when reminiscing about our efforts to represent the interests of genetic counselors in this process, “It was you and me against the world!” (Smith, 1994).

### **Continuing Education**

*From the onset, continuing education was an important goal for the new professional society, with strong leadership in this area provided by Beverly Rollnick who developed continuing education criteria (Rollnick, 1981).*

In addition to early regional educational conferences, there were educational programs at national meetings. The first two programs were single papers presented by invited speakers at NSGC business meetings: June 24, 1979 in Chicago, Beverly Rollnick, “The National Genetic Diseases Act,” and June 10, 1980 in New York City, Tabitha Powledge, “Moral and Political Dilemmas in Genetic Counseling.”

Then in 1980, the chairman of the 1980 ASHG meeting refused a written request to include the NSGC Educational Program and Business Meeting in the program of auxiliary meetings scheduled in conjunction with the ASHG meeting. At the Asilomar Conference the previous year, the same physician had objected to the concept of a national professional society for genetic counselors, predicting that national genetic counselor meetings would conflict with ASHG meetings and reduce attendance of genetic counselors at the ASHG meeting. Actually, the NSGC Board had already decided to schedule Annual NSGC Education Conferences to precede either the NF-MD or ASHG meetings to encourage genetic counselor attendance at both meetings. This anecdote illustrates the political climate of 1980. It is gratifying to compare the current recognition of the NSGC and genetic counselors at ASHG meetings.

On June 18 and 19, 1981 in San Diego, in conjunction with the MD-BDF conference, the NSGC held the first full-day Annual Educational Conference. The meeting chaired by Carolyn Bay, Susan Reed, and Elizabeth Thomson, with an organizational committee that included Diane Baker, Deborah Collins, Beth Fine, Audrey Heimler, Carolyn Lieber, Beverly Rollnick, Ann Smith, Deborah Timmons, and Linda Whipperman. The program, supported by a \$10,000 grant from the MD-BDF, was entitled "Strategies for Genetic Counseling: An Update." The program committee hoped the term "strategies" would be the key word for future programs, as indeed it was for the next decade. There were 182 registrants (out of a total membership of 400). The program included invited speakers, workshops, contributed papers, posters, and a media room assembled by Susan Schmerler and Lorraine Suslak to exhibit publications and audiovisual material relevant to genetic counseling. There was a sense of excitement, of having arrived. For many people, the meeting demonstrated that the Society could deliver the promise envisioned by the founders (NSGC, 1981).

When I asked Joan Scott to identify highlights of NSGC history, she replied, "National educational meetings were so successful. They contributed to a decrease in regionalism and enabled genetic counselors to see the usefulness of a national society" (Scott, 1994).

A milestone mini-event occurred when Ann Smith brought her infant son to the NSGC Annual Education Meeting in 1981 when she was installed as president. From that time, new parents have been comfortable attending meetings with their babies. Previously, the presence of a parent and a young baby might have been considered unprofessional behavior. New parents did not attend annual meetings unless they could leave their babies at home.

In 1984, the Third NSGC Annual Educational Meeting established two milestones. The theme of the meeting was "Clinical Investigation Studies"



which in the words of Beth Fine, conference chairperson, was “the first time ongoing genetic counseling research and the potential for genetic counselors to become involved in clinical studies were formally addressed.” Beverly Rollnick noted that *Strategies in Genetic Counseling: Clinical Investigation Studies*, published by the MD-BDF was “the first publication of the proceedings of a national educational conference” (Fine, 1984; Rollnick, 1984).

### NSGC Brochure

In 1980–1981, with support from the MD-BDF, the first NSGC brochure was published during Beverly Rollnick’s presidency. It included a brief history and definition of the NSGC (NSGC, 1980). The second edition, in 1983, included a much needed, but difficult to achieve, definition, “Genetic Counseling as a Profession” written by Beverly Rollnick and a collaboration of other genetic counselors, including myself (NSGC, 1983).

### NSGC Standing Committees

NSGC standing committees have made valuable contributions on issues of current or ongoing importance. For example, Ann Smith, one of the first genetic counselors with computer expertise, published the first computerized membership directory in 1981 while she was chairperson of the NSGC Social Issues Committee. Over the years, The Social Issues Committee developed significant position papers and organized a contingent of genetic counselors who went to Washington, DC in 1985 to participate in a national march to support pro-choice.

In December 1981, results of the first Professional Status Survey, compiled by Michael Begleiter, Debra Collins, and Karen Greendale for the Professional Issues Committee, was published in *Perspectives* (Begleiter *et al.*, 1981). Subsequent surveys reflect changes in membership and professional roles. Joseph McInerney shared with me his opinion that “The data collected via the professional issues surveys, disseminated in *Perspectives*, have provided ammunition for the members to seek better professional treatment and have illustrated the range of professional options open to those trained in genetic counseling” (McInerney, 1994). A Code of Ethics, adopted in August 1991 after 5 years of diligent work by an *ad hoc* NSGC Subcommittee on Ethical Codes and Principles chaired by Judith Benkendorf, embodies principles and standards for human issues of concern to a professional society such as the NSGC. The Code has attracted national and international recognition (Benkendorf *et al.*, 1992).

### NSGC Awards

The Special Projects Fund, NSGC's first award, established in 1990 with contributions from individuals, organizations, and companies, provides approximately \$2000 annually to one or more genetic counselors who are members in good standing of the Society for project(s) that focus on the future of the genetic counseling profession and/or the provision of genetic services (NSGC, 1989).

The Jane Engelberg Memorial Fellowship (JEMF), is an annual \$25,000 grant from the Engelberg Foundation to the NSGC established in 1991 by Alfred B. Engelberg in memory of his wife, Jane Engelberg, a genetic counselor who died in 1988. The JEMF is awarded annually to one or more than one genetic counselor(s) who are full members of the NSGC and ABMG or ABGC board certified (or have been granted active candidate status by the ABGC), for study, research, writing, or exploration of new interests in order to enhance present skills, develop new skills, contribute to the body of knowledge in the field of genetic counseling, or expand professional roles (Heimler, 1991).

### The Impact of NSGC on Professional Development

Genetic counselors have been eligible for membership, appointment, and election as representatives of the NSGC on many boards and standing committees including the ABMG, ASHG, American College of Medical Genetics, Council of Medical Genetics Societies, and, of course, the American Board of Genetic Counseling (ABGC).

Among the responses to letters I sent to genetic counselors nationwide to gather material for the 1994 NSGC Annual Educational Conference talk, were several that referred to the influence of the NSGC on the development of the genetic counselor as a professional. Deborah Eunpu wrote, "Without the NSGC, genetic counselors would not have developed such a strong professional identity, nor would they have had opportunities to learn leadership skills to such a great extent" (Eunpu, 1994). Ann Brown wrote that the NSGC has been a "positive influence" on the profession, and Joan Scott stated that "the NSGC has been...critical for the development of the profession" (Scott, 1994; Brown, 1994).

In 1985, Luba Djurdjinovic, NSGC president, appointed an *ad hoc* committee, chaired by Virginia Corson, to examine how genetic counselors have broadened their roles in traditional settings or found ways to apply their skills to jobs not envisioned when the role of the genetic counselor was developed. Thirty-seven genetic counselors who had unique job profiles

were selected for a survey. The results of the survey revealed a range of professional goals including academic appointments for teaching, research, and clinical skills, administrative responsibility for clinical programs, private practice, publishing professional literature, and continuation of clinical practice as the primary professional role. It was evident that a counselor's training is readily adaptable to a diversity of job settings, and personal factors are at least equally important for successful careers. The report concluded, "This receptiveness to opportunity in combination with the expansion of genetics services has opened new clinical, educational and administrative roles to genetic counselors" (Baker *et al.*, 1987).

Also in 1985, Luba Djurdjinovic created the position and appointed Bea Leopold as Executive Director of the NSGC. Many people noted the effectiveness of the new Executive Director. Robert Resta remarked, "This step moved the NSGC forward as a 'for-real' organization." (Resta, 1994). Vicki Venne wrote, "We had an executive director relatively early in our organizational life, and I think that impacted the direction of our organization...creating a central hub around which...our...communication could swirl" (Venne, 1994). Joan Scott commented, "The executive director helped us to consider long range planning, establish a data base, and to relate the operation of the Society to the membership" (Scott, 1994). In addition, Bea Leopold played a pivotal role in the long-range planning process begun in 1990, which resulted in the creation of a panel of NSGC past-presidents to develop vision and mission statements for the Society and the contracting of a strategic plan to achieve NSGC goals.

In 1992, while not all genetic counselors were in favor of "restructuring" (Heimler *et al.*, 1992), diplomates of the ABMG voted to disassociate the genetic counselor category of certification and membership in order to qualify the ABMG for membership in the American Board of Medical Specialties (Epstein, 1992). With a financial settlement from the ABMG, genetic counselors elected a board of directors and established the ABGC, Inc. empowered to write the genetic counseling certification examination, certify genetic counselors, and determine accreditation eligibility for training programs who are mandated, after a grace period, to hire board-certified genetic counselors as directors. Self-determination for genetic counselors was a reality.

## CONCLUSIONS

In 1980, in her presidential address, Beverly Rollnick said, "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 coun-

selors met in 1978, they were aware of the forces in motion. These forces were affecting professional status of large numbers of genetic counselors who were working in a variety of settings across the country: genetic counselors who had no unified voice. It was time to organize. The NSGC was formed in this context to represent genetic counseling professionals" (Rollnick, 1980).

Barbara Biesecker sent me the following statement about her term as NSGC president, 1989–1990, "The NSGC had moved beyond establishing itself, obtaining recognition and an identity. The field had arrived. There were no longer huge issues of public awareness and acceptance, territorialism with physicians or nurses, or fantastic confusion of genetic counseling and abortion. We were ready to vote in a professional journal, to establish a professional literature, and to form position statements. We had something to say, and we weren't afraid to say it. We were moving more into the social and legislative issues that affect our practice as counselors. And we had become mature enough to recognize that we had become diverse, specialized and experienced and were no longer necessarily of one mind on the issues. There was need for debate and discussion and thus, professional self-confidence" (Biesecker, 1994).

Joan Weiss, MSW, an NSGC founding associate member and a participant in the 1979 Asilomar Conference, when asked for her recollection of the formative years of NSGC history replied, "I remember the Asilomar Conference in 1979. It was obvious that the genetic counselors were put on the defensive in a hostile environment. It is amazing, given the struggle they had in the beginning, that only fifteen years later genetic counselors are now so well-respected and accepted in the same medical community. With a handful of leaders, they taught everyone what they can do" (Weiss, 1994).

In her Presidential Address in 1992, Elizabeth Gettig stated, "The NSGC has a tradition of strong leadership. The leaders of yesterday had the goal of establishing a Society. The leaders of today have the task of determining the future goals of your Society" (Gettig, 1992).

In 1979, The Committee to Form the NSGC wrote the following statement of purpose for the proposed professional society: "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 interest of genetic counselors; and, generally, to be responsive to issues related to the field of human genetics..." (NSGC, 1979). This purpose has been realized.

## ACKNOWLEDGMENTS

I dedicate this history to the memory of my dear friend, Beverly R. Rollnick. She played an important role in the introduction to the medical genetics field of a master's level genetic counselor, and then guided and inspired the development of the National Society of Genetic Counselors. I am grateful to my friends and colleagues who wrote or talked with me to provide material for this paper.

## REFERENCES

- Baker DL, Benkendorf J, Heimler A, Kramer D, Nakata N, Smith ACM, Corson V (1987) Report from the *ad hoc* Committee on the Expanded Roles of Genetic Counselors. National Society of Genetic Counselors publication.
- Bay C (1994) Personal communication.
- Bearn A, Cogan EJ, Littlefield J, Motulsky AG, Robinson A (1973) Report of a Site Visit of the Advisory Committee to the Human Genetics Program of Sarah Lawrence College. Site visit report, Sarah Lawrence College Archives.
- Begleiter ML, Collins DL, Greendale K (1981) NSGC professional status survey. *Perspect Genet Counsel* 3(4):1-2.
- Benkendorf J, Callanan NP, Grobstein R, Schmerler S, FitzGerald KT (1992) An explication of the National Society of Genetic Counselors (NSGC) Code of Ethics. *J Genet Counsel* 1(1):31-39.
- Biesecker BB (1994) Personal communication.
- Brown A (1994) Personal communication.
- Djurdjinovic L (1994) Personal communication.
- Epstein CJ (1973) Who should do genetic counseling and under what circumstances? *Contemp Genet Counsel. BD:OAS* 9(4):39-48.
- Epstein CJ (1992) Organized medical genetics at a crossroad. *Am J Hum Genet* 51:231-234.
- Eunpu DL (1994) Personal communication.
- Fine BA (1984) Introduction. In: Fine BA, Paul NW (eds) *Strategies in Genetic Counseling: Clinical Investigation Studies. BD:OAS* 20(6):1-2.
- Gettig E (1992) A joint partnership between leaders and membership. *Perspect Genet Counsel* 14(4): p. 2.
- Heimler A (1979) From whence we've come: A message from the president. *Newslett Nat Soc Genet Counsel* 1(1):1.
- Heimler A (1980a) Report on the Business Meeting of the NSGC, Inc. *Perspect Genet Counsel* 2(3):1-2.
- Heimler A (1980b) Opening remarks 1980 business meeting. *Perspect Genet Counsel* 2(3):1.
- Heimler A, Benkendorf J, Biesecker, BB, Greendale K, Kloza E (1991) Fellowship Enhances Genetic Counseling Profession. *Perspect Genet Counsel* 13(4):9.
- Heimler A, Benkendorf J, Gettig E, Reich E, Schmerler S (1992) American Board of Medical Genetics restructuring: Make an informed decision. *Am J Hum Genet* 51:v-vii.
- Ingall GB (1979) Personal communication.
- Klass P (1979) The professional issues committee: A report. *Newslett Nat Soc Genet Counsel* 1(1):2.
- Klass P (1994) Personal communication.
- Lustig L (1994) Personal communication.
- Marks J (1994) Personal communication.
- Mertens TR, Hendrix JR, Kenkel KM (1986) The genetic associate: A career option in genetic counseling. *J Hered* 77:175-178.

- McInerney JD (1994) Personal communication.
- NSGC (1979) By-Laws of the National Society of Genetic Counselors, Inc., NSGC Archives.
- NSGC (1980) A publication of the NSGC.
- NSGC (1981) Strategies in Genetic Counseling: An update. National Society of Genetic Counselors First Annual Educational Conference Book, National Foundation–March of Dimes.
- NSGC (1983) A publication of the NSGC.
- NSGC (1989) Special Projects Fund. The Future Holds Much Promise. A publication of the National Society of Genetic Counselors commemorating the tenth year of the National Society of Genetic Counselors, p 7.
- NSGC (1991) Jane Engelberg Memorial Fellowship. *Perspect Genet Counsel* 13(4):9.
- New York State (1979) Certificate of Incorporation of the National Society Inc.
- Resta R (1994) Personal communication.
- Rollnick BR (1980) Why a national society of genetic counselors? *Perspect Genet Counsel* 2(3):3-5.
- Rollnick BR (1981) Continuing education criteria: A proposal presented to the Annual Membership Meeting of the National Society of Genetic Counselors, Inc. *Perspect Genet Counsel* 3(4):2-4.
- Rollnick BR (1984) The National Society of Genetic Counselors: An historical perspective. In: Fine BA, Paul NW (eds) *Strat Genet Counsel: Clin Invest Stud. BD:OAS* 20(6):3-7.
- Rubin SP (1979a) Minutes: Committee to Form the National Society of Genetic Counselors *ad hoc* Board of Directors Meeting, March 4, 1979, NSGC Archives.
- Rubin SP (1979b) Minutes: Committee to Form the National Society of Genetic Counselors *ad hoc* Board of Directors Meeting, June 26, 1979, NSGC Archives.
- Rubin SP (1979c) Minutes: Committee to Form the National Society of Genetic Counselors *ad hoc* Board of Directors Meeting, October 4, 1979, NSGC Archives.
- Scott JA (1994) Personal communication.
- Smith ACM (1994) Personal communication.
- Suslak L (1979) Minutes: Committee to Form the National Society of Genetic Counselors *ad hoc* Board of Directors Meeting, May 29, 1979, NSGC Archives.
- Thomson EJ (1994) Personal communication.
- University of California, Irvine, Division of Clinical Genetics and Developmental Disabilities, Department of Genetics (1979) Genetic Associates: Their Training, Role and Function. U.S. Dept. Health, Education and Welfare, Health Service Administration Publication, pp 1-42.
- Venne V (1994) Personal communication.
- Walker AP (1979) Asilomar east. *Perspect Genet Counsel* 1(3):1-4.
- Weiss JO (1994) Personal communication.