

The National Society of Genetic Counselors (NSGC)

Audrey Heimler and colleagues founded the National Society of Genetic Counselors (NSGC) in 1979 in New Hyde Park in New York, New York. Her stated goals were to establish the field of genetic counseling within biomedicine and to coordinate counselors' voices, so that physicians and others in the medical industry would not dictate the future of the field. Genetic counselors inform patients about the potential for inherited diseases passed on through family lineages and help to navigate the options available. NSGC helped establish the field of genetic counseling by formulating guidelines for accreditation in university programs, establishing curriculum for continuing education of members, and creating committees to respond to issues that pertain to genetic disorders and the way they are presented to patients. As scientists continue to research the human genome, particularly in the area of prenatal genetics, an area of medicine that allows physicians to diagnose the health of the fetus prior to birth, genetic counseling is an established field in reproductive medicine.

Joan Marks, the director of the Human Genetics Program at Sarah Lawrence College in Bronxville, New York, proposed the idea of creating a professional society for genetic counseling in 1977. She discussed that with a few interested students who had recently graduated from her program or who were still working toward their degree. Deborah Eunpu, one of the recent graduates from Sarah Lawrence College, began contacting professionals who practiced in genetic counseling and directors of genetic counseling training programs in the country. In 1978 Marks invited Eunpu, Luba Djurdjinovic, Debra Timmons, and Joan Scott to a postgraduate seminar in Bronxville, New York, to help establish a society. Of the practicing counselors that normally attended the seminar, Lorraine Suslak advocated for the new society and convinced Heimler and her team that they needed a dedicated advocacy group for the field of genetic counseling. Marks organized another meeting in 1978, with more students, directors, and alumni of three genetic counseling programs in Rutgers University in New Brunswick, New Jersey, Stony Brook University in Stony Brook, New York, and Sarah Lawrence College. Heimler chaired the meeting and nearly 100 genetic counselors at the meeting decided to work towards the establishment of a national society.

In April 1978 nine of the founders, Heimler, Suslak, Eunpu, Djurdjinovic, Niecee Singer, Sylvia Rubin, Hody Tannenbaum, Evelyn Lilienthal, and Phyllis Klass, established the Committee to Form the National Society of Genetic Counselors. They met biweekly in New Hyde Park to structure bylaws, rules to organize the internal operations and business transactions, for the new organization. The committee decided to nominate and elect an ad hoc board of directors for the purpose of establishing bylaws and responsibilities. There could be no elections for a board of directors until there were official members, and there could be no official members until there were bylaws written. Heimler was elected as the president, Suslak as the vice president, Rubin as the secretary, Singer as the treasurer. The committee also established five committees, the By-Laws Committee, Education Committee, Membership Committee, Professional Issues Committee, and the Social Issues Committee. Tannenbaum was elected as the By-Laws Committee chair, Judith Dichter and Roberta Spiro as the Education Committee chairs, Lilienthal as the Membership Committee chair, Klass as the Professional Issues Committee chair, and Ann Walker was elected as the Social Issues Committee chair.

In October 1978 Heimler and the ad hoc board of directors held a meeting, corresponding to the American Society of Human Genetics meeting, in Vancouver, Canada. The intention was to ensure there was national dialogue with genetic counselors about the foundation of the society. While the larger group lacked unanimity in the decision to form the society or how to form it, the original members nonetheless pressed forward. Over the following fourteen months, the ad hoc board of directors laid the foundation of the organization until a formal election took place.

During 1978 and 1979 the ad hoc committee established the original bylaws to define the name of the organization, the criteria for membership, and the mechanism by which they would be a nationally representative body for genetic counselors. The group had trouble deciding what to name the organization because of national arguments over the terms genetic counselor or genetic associate. Some of these national conversations took place at three separate Asilomar conferences, formally known as meetings of the International Congress on Recombinant DNA molecules. These meetings were held with panels of physicians and researchers to discuss their responsibility with new genetic information and technology. Since genetic counseling was new to the clinical world, genetic counselors and clinicians discussed how to integrate the specialists into clinical practice to explain to patients about the potential for inherited diseases.

Heimler later stated that genetic counselors at the third Asilomar conference refused to compromise their title, seeing associate as diminishing to their profession. Although the founding board of directors for NSGC had already established their view that genetic counseling should be the term used for their field before the Asilomar conference, they were unable to voice their opinion from a national organization. With significant pressure from genetic counselors in the room, the issue was finally settled with genetic associate as the term for any student in an established training program, and genetic counselor as the provider for the service.

The Membership Committee, chaired by Lilienthal, was in charge of deciding the standards for eligibility as well as the categories of membership for the organization. The committee discussed that the membership criteria would be a board certification. However, due to the fact that board certification for genetic counselors was still in discussions in the American Board of Medical Specialties, they decided to instead describe the criteria for membership in hopes that it would be the model of the official board certification as well. It was not until 1981 that the American Board of Medical Genetics was established and began the task of outlining the standard of curriculum and training for genetic counseling certification programs. Guidelines were set for full membership, and to get it, an individual had to hold a PhD or master's degree from a certified genetic counseling program. The committee also took into consideration the 1979 Asilomar conference that brought about an argument about physician's discontent about being excluded from membership to the national organization. There were no concessions made during the conference by the genetic counselors present, but later the NSGC ad hoc board of directors held conversations surrounding the valuable contributions of other professions within the medical communities. NSGC then established associate membership for physicians, nurses, social workers, and dentists that have interests focused on genetic counseling or the impact of inherited genetic diseases and disorders on their profession.

The By-Laws Committee also established a way to maintain national representation in the organization. Heimler and the ad hoc board of directors were all from the East coast of the US, which caused concern for geographical representation and perspective. To change this, the committee wrote the bylaws to include six geographically distinct regions, which they called regions one through six, and that each region would have its own director. Regional directors were immediately sought, and regional conferences were started in 1979.

By the end of 1979, NSGC had two hundred and twenty-seven members from all over the nation, and they paid ten dollars as a membership fee. The ad hoc board of directors voted on and passed the bylaws for NSGC in June 1979. On 1 October 1979 NSGC was incorporated as a non-profit organization in the New York state. In an attempt to have a more central location, the first business meeting of the organization was held three days later on 4 October 1979 in Minneapolis, Minnesota during a NSHG conference.

In 1979, NSGC's first publication came out, titled, A Newsletter of the National Society of Genetic Counselors, edited by Eunpu. Klass, the appointed Chairperson of the Professional Issues Committee, wrote an article in the newsletter that criticized the American Society of Human Genetics' genetic counselor task force. Klass argued that the task force had no appointed members with a PhD. ASHG did not respond to the original request. After a second statement that criticized non-representative leadership in the next NSGC publication, Klass was asked to serve on ASHG's genetic counselor task force to represent members of the field without a PhD. The American Board of Human Genetics was established as another governing body for genetic service professionals in 1981. Due to Klass's persistence with ASHG, the ABHG board of directors received two seats

for NSGC members on their board of directors, expanding the genetic counselor's representation nationally.

NSGC's first open election was held in 1980. Thereafter, with annual publications sent out to all of its members, NSGC began successfully completing its mission to disseminate information out to genetic counselors nationwide. In 1992 the first version of the *Journal of Genetic Counseling* was published based on the findings and standings of topics relevant to genetic counseling such as biomedicine, ethics, and education. The journal consisted of peer-reviewed articles, research findings, and recommendations from the NSGC body. The topics covered in the articles are extensively broad, covering miscarriage to particular genetic diseases such as Fragile X syndrome, a genetic condition that affects learning abilities and cognitive developments.

With a code of ethics, NSGC responds almost on an annual basis with formal statements about the organization's stance about ethical issues affecting medical genetics. As genome scanning becomes cheaper and therefore more accessible, the correct presentation of the information becomes even more critical. As an example, in 2004 NSGC released a formal statement about their recommendation on inherited genetic cancer risk and counseling. The document includes counseling recommendations from intake to follow-up, current information about population statistics for risk of cancer, and a small discussion on a minor's ability to consent to genetic testing to ascertain risk.

NSGC also lobbies for favorable legislation in the federal government. Their lobbying team has worked on many different legislative pieces such as the addition of conscience clauses to state licensures.

Sources

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