The National Society of Genetic Counselors (NSGC) [1]

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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 [3], particularly in the area of prenatal genetics, an area of medicine that allows physicians to diagnose the health of the fetus [4] 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 [5]. 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 [5] 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 [5], 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 [5] 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 [5]. 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.
Sources

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