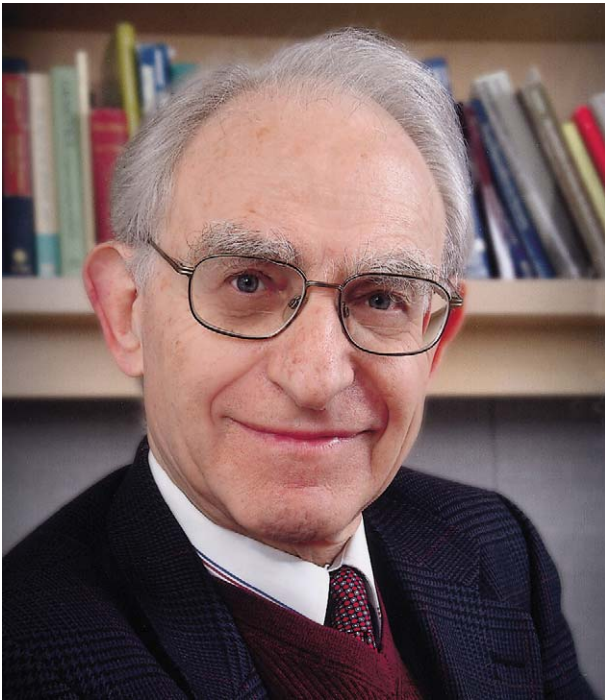


## 2003 ASHG AWARD FOR EXCELLENCE IN HUMAN GENETICS EDUCATION Introductory Speech for Joan Marks\*

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The Award for Excellence in Human Genetics Education is given every year for work of exceptional quality and great importance. Our Society defines education broadly and presents this year's award to Joan Marks for her major impact as a pioneer who shaped the new profession of genetic counseling. She is generally considered to be the "mother" of this field.

Who is Joan Marks, and what has she done? Born in Portland, Maine, she attended Sarah Lawrence College (the site of her future triumphs), followed by graduate

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studies in social work at Simmons College in Boston, where she obtained a master's degree in social work. She then worked as a psychiatric social worker at several major New York teaching hospitals. In 1972, Joan became the director of the newly instituted genetic-counseling program at Sarah Lawrence College, in Bronxville, New York, initially conceived by Melissa Richter in 1968–1969, who unfortunately died of breast cancer somewhat later. Joan served as director of this program for 26 years, until 1998.

Building on small beginnings, Joan possessed vision, energy, and administrative and diplomatic skills to shape the Sarah Lawrence program as a model for education in the new profession of genetic counseling.

The concept was to teach post-baccalaureate students the scientific principles of human and medical genetics, together with the fundamentals of counseling, including its psychological aspects. Joan herself taught a course on the psychological elements of the genetic counselor's responsibilities. At home, Joan had not only moral support but also scientific help. Her husband, Paul Marks—a well-known hematologist and cancer expert, who worked on the genetic red-cell trait of G6pd deficiency when Joan started at Sarah Lawrence—tutored her in genetics in the early days.

Joan attracted faculty members with different academic specialties to teach courses such as human genetics, cytogenetics, clinical medicine, biochemistry, reproductive genetics, embryology, and others. Students were then introduced to families and patients with various genetic diseases in several genetics clinics in the greater New York area, and they obtained a master's degree in a 2-year program. Early students in the program were women who had completed their families and were looking for a stimulating new educational experience and career. Later, women of a younger age and a few men became the typical students. Medical geneticists and genetic counselors unaffiliated with the program provided outside advice. Since I had the privilege to serve on the board of the Sarah Lawrence Genetics Counseling Program, I got to know Joan and the program well.

Funding was never easy. Sarah Lawrence College was not known for its scientific or medical orientation, and Joan had to apply her talents and vision to sell various governmental organizations and foundations on the im-

portance of and needs for genetic counselors. She succeeded remarkably well. One example: she was able to raise money personally for a scientific genetics training lab for her students. Joan's vision and sound judgment led to her being appointed to a variety of policy-making task forces and commissions spanning a variety of disciplines. The American Board of Internal Medicine, for example, made her an advisor.

Currently, there are about 600 graduates of the program, which means that approximately a third of genetic counselors in the U.S. obtained their degrees at Sarah Lawrence College. The program has grown, with 47 students currently enrolled in the program and 19 affiliated faculty members. Twenty-five other genetic counseling programs exist in the U.S.A., and a few others exist in countries such as Canada.

Practically all such programs are built on the Sarah Lawrence model, and about one-half are directed by Sarah Lawrence graduates. One of our colleagues put it this way: "When someone is a Sarah Lawrence graduate in human genetics, one is identified as coming from a program of rigor and excellence with the very highest standards."

Joan's influence on the field of genetic counseling has been enormous. From early beginnings, when Sarah Lawrence graduates were known as "genetic associates," the field has become fully professionalized. It became clear with advances in medical genetics and increasing demand for services that there would not be a sufficient number of M.D. medical geneticists to provide the necessary work force. Modern clinical genetics that is responsive to genetic as well as psychosocial problems could not be carried out as fully or as well without genetic counselors trained in the Sarah Lawrence model.

A well-known medical geneticist states that genetic counselors are the backbone and heart of clinical genetics services. As another colleague put it, "I rely on the skills, devotion, intellectual prowess, caring, and insights of genetic counselors in every working moment of my professional life."

About 40% of genetic counselors work in university medical centers, and another 40% in hospitals, medical facilities, and HMOs. New scientific advances open up completely new areas of activities. For instance, cur-

rently, about 40% of counselors include some aspects of cancer genetics in their work.

To be certified in their field, genetic counselors had to pass the same basic genetics examinations as all other M.D. and Ph.D. genetic specialists tested by the American Board of Medical Genetics (ABMG). Since 1992, genetic counselors have had their own specialty board with high standards, which uses the same basic genetics tests as the ABMG. Furthermore, genetic counselors are tested on the psychological and social aspects of genetic counseling. In addition to counseling based on solid scientific and medical data, as well as psychological insight, genetic counselors teach at many levels, are case managers and advisors to patient-group associations, and are being increasingly employed by diagnostic laboratories.

Genetic counselors are becoming involved in clinical genetic research activities. To cite a recent example: the New York Breast Cancer Study, directed by my Seattle colleague Mary-Claire King as well as by Joan Marks, includes as coauthors 38 genetic counselors. Furthermore, more than 100 graduate students from the Sarah Lawrence program were interns on the program and critical to its success. The results (*Science* 302:643–646, 2003) showed that the lifetime breast cancer risk for BRCA1 and BRCA2 carriers is more than 80%—regardless of family history—and that breast cancer appears earlier among mutation carriers born after 1940. Furthermore, healthy weight and more physical exercise in adolescence reduce the breast cancer risk. An unusual feature of this study was that results of genetic testing were provided in the context of genetic counseling to each participant during the course of the study. Such integration of genetic counseling into clinical genetic research may become more common in the future.

The bestowal of the Education Award to Joan Marks honors the principal architect of a new independent profession that has become essential for all aspects of clinical genetics. The presentation of this award to Joan Marks by the American Society of Human Genetics symbolizes the recognition of genetic counseling by the community of human geneticists. Congratulations to Joan—its visionary pioneer—and to all genetic counselors!