

Editorial

This special issue of the *International Journal of Human Genetics* is dedicated to feature different aspects of genetic counseling. The fifteen papers in this issue span cover topics on the scope of genetic counseling, recent advances in the field of Genetics, disease specific findings, test services, ethical issues and genomic trends in India. In this introduction, the researchers have reviewed the brief history and the advances in genetic counseling. The researchers hope to encourage young professionals and scientists to be part of this rapidly expanding field of genomic medicine and pursue further research.

The term “genetic counseling” was coined by Sheldon Reed, a geneticist at Dight Institute for Human Genetics at the University of Minnesota, in the late 1940s after he began receiving questions from physicians about genetic conditions. As his ideas became well-known, there was a demand for genetic counseling professionals. Melissa Richter took matters into her own hands, and established the first Master’s Degree genetic counseling program at the Sarah Lawrence College in 1969. The program provided training in both genetics and psychosocial support. Originally, genetic counselor training programs were accredited by the American Board of Medical Genetics, but, as the field grew, the American Board of Genetic Counseling and the Accreditation Council for Genetic Counseling were created for program accreditation and board certification exams. With a new line of professionals becoming available, the National Society of Genetic Counselors was formed to provide a communication network and support professionals.

Professional genetic counselors’ seek to learn about the genetic conditions, determine potential familial heredity of the variation, and aid patients in making non-directive decisions about testing and treatment options. To do this, genetic counselors work alongside clinicians, laboratory personnel and a variety of other professionals across different disciplines. When the team consults the patients, the genetic counselor is responsible for obtaining family medical records, discussing genetic conditions and their potential impacts on the patient, coordinating genetic lab testing, explaining the implications of testing, evaluating responses to test results,

providing appropriate counseling and community resources, and documenting information for families and healthcare professionals. Genetic counselors work in several areas of medicine (cancer, prenatal, pediatric, infertility, pharmacogenomics and adult) and with the advent of recent advances in the genomic technologies, that has rustled in the expansion of their roles outside of the clinical practice into research, education, public health, administration, professional development, consulting and industry settings.

Even with the exponential growth, genetic counselors remain as a small group of experts across the globe, with around 4000-5000 certified counselors in the US and Canada, 300 in UK, 200 in Europe, 280 in Australia and a few 100s in Asia. Major funding and research efforts like the 100,000 Genomes Project in the UK and the Precision Medicine Initiative in the US are paving the path to better understand the impact of genomic variants, rare inherited disorders and its interaction with the environment. Coupled with the lower costs of DNA analysis and sequencing, companies and institutions are also offering more testing services, sometimes directly to the consumers. This has lead to a higher demand for professionals (like genetic counselors) who are trained to make sense of the complex information, translating them it into clinical practice and enabling genomic advances across different disciplines. It is not surprising that the US Bureau of Labor predicts a twenty-nine percent growth rate for genetic counseling jobs between 2014-2024, when the average rate of growth across other occupations is around seven percent.

The public is gaining higher expectations and knowledge in genomic testing due to the readily available information on the web and direct-to-consumer advertising for certain genetic tests. Despite their interest in testing, the public does not fully understand the complexities and underlying nuances of genetics. Genetic counselors must provide families with appropriate pre-test counseling and follow-ups to help them understand pros and cons of the screening tests, medically actionable results, incidental findings, results that they did not expect, negative results,

and variants of uncertain significance. The recent increase in genetic testing also requires more clinicians to be educated about the process of performing genomic testing and its implications, a task genetic counselors have taken on. This necessitates that genetic counselors remain up to date on the latest technologies and resources available to them, provide insight and interpretations of test results and how to proceed with them, and understand the impact of results on the families.

Through this special issue, the researchers hope to encourage young professionals to pursue genetic counseling and realize the importance of their role in public health and genomics. This issue only touches on a fraction of the wealth of the new information and trends in genetics. The researchers look forward to seeing more genetic counselors lead the way to a future of improved health care and personalized genomics.

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