

## Editorial Commentary

### Second World Congress on Genetic Counseling: An Introduction to the Special Issue

Alison McEwen<sup>1</sup>, Christine Patch<sup>2,3</sup> and Barbara Biesecker<sup>4</sup>

1. Genetic Counseling, Graduate School of Health, University of Technology Sydney, New South Wales, Australia
2. Society and Ethics Research, Connecting Science, Wellcome Genome Campus, Hinxton, UK
3. Genomics England, London, UK
4. Research Triangle Institute, International, Washington D.C., United States

Corresponding author: Alison McEwen, Graduate School of Health, University of Technology Sydney,  
PO Box 123 Broadway NSW 2007 Australia

This Journal of Genetic Counseling Special Issue highlights invited papers that reflect emerging themes discussed at the second World Congress of Genetic Counseling, held at the Wellcome Genome Campus in Hinxton, United Kingdom in October 2019. Reflecting on the Congress at the end of 2020, in a changed world, the authors recall the excitement of sharing an auditorium with nearly 200 genetic counselors from 26 countries. Presentations highlighted the remarkable advances in genomic science and with them, the expanding opportunities for genetic counseling and related research. We further recall various tensions generated by a rapidly expanding genetic counseling profession that is seeking to upscale and increase our reach, and to maintain and grow our roles as counselors, while remaining true to the ethical foundations of the profession. As genetic counselors create novel opportunities to use the tools of genomic science, we aim to retain the priority to facilitate therapeutic counseling with individuals and families who are living with or at risk for inherited conditions.

Technology that facilitates access to genetic and genomic information and to the promises of precision medicine is now being integrated into clinical care. Genetic counselors are taking up opportunities to be part of the delivery of this technology, bringing their professional values with

them. For example, genetic counselors are involved in the development and delivery of digital tools such as chatbots and online information resources that extend our reach beyond tertiary care centers and into communities. Used strategically, these tools can guide referrals and help genetic counselors free up valuable time for the clients who can benefit from our specific skills as counselors. A commentary by Shivani Nazareth and colleagues, in this issue, describes the value of integrating chatbots into care models and the asset genetic counselors can be in their development.

The facilitation of a therapeutic alliance to conduct psychological counseling within the context of genomics is the 'what we do' that defines genetic counseling. Here Lori Erby and colleagues introduce their research on assessing the therapeutic alliance. Rhona Mcleod and collaborators illustrate how genetic counsellors, in partnership with other therapists, are using narrative therapy with those living with a family history of Huntington disease. As a profession, we have the rare privilege of engaging with clients and their families, listening, and reflecting back in a trustworthy relationship in which they can share their thoughts and feelings to help make meaning of their experiences. Demonstrating our ability to do so through research will provide further credibility to the importance of counseling skills in conveying genomic information. Galen Joseph and colleagues share a definition of usual care in genetic counselling in this issue to be used to guide design of the standard care arm in trial studies.

For many of us, this opportunity to connect with patients is the reason we entered this profession. The challenge, as we see it, is to continue to innovate ways forward in which genetic counselors can use our specific skills and interests, with technologies and directly with clients and family members, while maintaining a strong collective professional identity. Gathering at the second World Congress provided opportunities to learn about a variety of practice models and differing roles of genetic counselors. In this issue Fiona Lynch and colleagues describe challenges and opportunities for genetic counselors in rapid acute care genomics. In some countries the roles of genetic counselors remain limited. Although increasingly the majority of master's level trained counselors around the globe have responsibilities for effectively increasing understanding of relevant genomics and enhancing the psychological wellbeing of their clients and family members. The variety of practice models have since been further expanded by the COVID-19 pandemic and the need for virtual care. The increasing importance of genomics across medicine and health care also provides the opportunity for working collaboratively with all members of the healthcare team highlighting the relevance of the skills and knowledge of genetic counselors to patient and client care.

Collectively, the themes of the World Congress recognize that the profession is experiencing a period of rapid growth and turbulence, as core values, principles and ways of working are challenged by

emerging technologies, a need to rapidly scale up, and recognition that other healthcare professionals can and will do aspects of the delivery of genetic and genomic healthcare. Genetic counselors are taking up opportunities to use their skills in novel ways. Michelle Bishop took her genetic counseling skills into the policy environment and found that her training and experience as a genetic counselor prepared her well. Her experiences, along with those of Alison McEwen and Chris Jacobs in preparing the future genetic counseling workforce for the uncertainties and opportunities that come with times of rapid change are included in this issue.

We recognise that genetic counseling differs across borders, sometimes subtly and other times markedly. While not all countries represented at the 2019 World Congress appear in this special issue, the perspectives represented include those from countries where genetic and genomic counseling are well-developed and where professional regulation/registration/licensure is in place, and from countries where the profession is emerging and finding a place in the delivery of healthcare.

Here Laura Hercher suggests the profession has entered adolescence, with the accompanying struggles to articulate a clear and individualised identity that typifies the developmental stage. This may be true in North America, The United Kingdom and Australasia, yet the status of genetic counseling varies, and the profession is younger and/or smaller in countries such as Israel and Hong Kong, as represented by contributions in this issue. Each country faces opportunities and challenges that reflect the culture and healthcare system genetic counselors work within.

While the profession is at different stages globally, there are similarities among the issues we all may grapple with. The importance of diversity and inclusion is highlighted in the work of Felicity Boardman, exploring the lived experience of disability as reproductive carrier screening and prenatal testing call into question the ways societies view disability. Reubs Walsh and Alexander von Vaupel-Klein provide a trans-perspective and a detailed overview of many aspects of working with transgender people.

The research and experiences brought together at the World Congress, and now in this Special Issue, capture the rich diversity of perspectives and uphold the shared value-base of our profession. We thank Christina Palmer, Editor-in-Chief, for the opportunity to curate this issue.