

PERSPECTIVE

The European Board of Medical Genetics: development of a professional registration system in Europe

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I am the first Chair of the European Board of Medical Genetics (EBMG), and my professional background is genetic nursing and genetic counselling. As is evident from the many contributions in this 50th anniversary issue, the ESHG has developed markedly in the past few decades and this development has included the inclusion of genetic nurses and genetic counsellors as part of the ESHG ‘family’, alongside the medical and laboratory colleagues who have long provided genetic services.

How was the EBMG conceived? In the early years of this millennium, it became clear that the professions that provide clinical services in Europe were growing, but there was little cohesion between countries and a lack of coherent educational standards. The funding available via the EuroGentest project enabled work to be focused on setting competences for European genetic professionals.¹ This, in turn, led to the establishment of three *ad hoc* committees to look at professional educational standards, on the initiative of Joerg Schmidtke. Much foundation work was achieved by those committees, including drafting core curricula for genetic nurses and counsellors and clinical laboratory geneticists.

It was evident that taking a more enduring and stable approach to this important work was appropriate and, building on the work of those committees, the ESHG gave birth to The European Board of Medical Genetics in Nuremberg in June 2012. The aim of the EBMG was to enhance patient care and patient safety by establishing professional standards of education, training and practice in human and medical genetics and genetic counselling. The focus of the work has been development of systems of certification and/or re-certification for professionals working as specialists in genetic healthcare in Europe.

Although the EBMG was formed under the auspices of the ESHG and was initially responsible to the ESHG Board and membership, it became clear that to maintain professional credibility it needed to be fully autonomous. It was decided at the ESHG Council meeting in Paris in 2013 that the EBMG should be established as a legal entity separate from the ESHG to provide greater legitimacy for the Board and those registered by the Board. This process of progression to autonomous adulthood was completed by June 2014, when the first General Assembly of the EBMG was held.

As this was an important step forward for the EBMG, we were intent on retaining substantive links with the ESHG. The statutes therefore state that although the EBMG is an independent body for the purposes of setting professional standards and operation of registration processes, to ensure the work of the EBMG remains current and informed by professional practice, the EBMG remains affiliated with

the ESHG. The statutes state that three ESHG members should be on the EBMG, and the EBMG Chair has a place on the ESHG Council. The EBMG website is also hosted by the ESHG (<https://www.eshg.org/413.0.html>).

The EBMG comprises three distinct professional branch boards, Clinical Laboratory Geneticists (CLGs), Genetic Nurses and Genetic Counsellors (GNGC) and Clinical Genetics and Genomics (CGG) (representing medical geneticists). While co-ordinating their efforts to improve standards of clinical care for patient in Europe, each branch addresses the needs of the professionals working in each specific discipline.

Two branches, CLGs and GNGC, have established systems of professional registration for practitioners. These had not been previously available in many European countries. Both branches have produced required standards of competence and education, on which rigorous systems to assess the competence of practitioners are based. Resulting from the assessment of applicants, there are now over 330 European registered Clinical Laboratory Geneticists and over 70 European registered Genetic Counsellors/Genetic Nurses. Full reports of the work of these branches have been published.^{2,3}

The EBMG section for medical geneticists (clinical genetics and genomics) has consistently worked alongside the UEMS Section for Clinical Genetics. This has enabled maximum effort in setting and ensuring standards for the profession. The curriculum for specialist training for medical geneticists in Europe has been updated and a suggested syllabus for training of residents in clinical genetics has been prepared. These important documents will serve as a base for a European examination in medical genetics. Further information is available in a separate article in this issue.

As is the case with most professional organisations, the members of each branch contribute considerable amounts of their time on an entirely voluntary and unpaid basis, and the success of the registration schemes is due to their diligence and generosity. Among the challenges has been making the registration system accessible to all who wish to validate their professional competence in this way, while ensuring standards are appropriate and the EBMG is financially viable. However, with the support of so many conscientious members, I have no doubt that the EBMG will continue to develop and adapt to the changes to clinical genetic practice in the future.

Postscript: Many changes have occurred since I first attended a meeting of the ESHG in 1997, in Genoa. I had been invited to contribute to an innovative workshop on genetic counsellor training and education, organised by Domenico Coviello. Apart from that workshop, there was little focus at the ESHG on genetic counselling,

and I have to admit to feeling very alone at that first meeting, spending many hours in front of posters, as I knew virtually no-one. I remember one day standing in front of a poster, wondering if I could venture to speak to the person who came to view it beside me. I sneaked a look at his name tag and scuttled away—it was Victor McKusick, a name known only too well to me as the author of the weighty tome I hauled to genetics clinics. Now, genetic counsellors form a considerable body of members of the ESHG....times have certainly changed....

- 1 Skirton H, Lewis C, Kent A, Coviello DA: Genetic education and the challenge of genomic medicine: development of core competences to support preparation of health professionals in Europe. *Eur J Hum Genet* 2010; **18**: 972–977.
- 2 Liehr T, Carreira IM, Aktas D *et al*: European registration process for Clinical Laboratory Geneticists in genetic healthcare. *Eur J Hum Genet* 2017; **25**: 515–519.
- 3 Paneque M, Moldovan R, Cordier C *et al*: Development of a registration system for genetic counsellors and nurses in health-care services in Europe. *Eur J Hum Genet* 2016; **24**: 312–314.



Heather Skirton is Professor of Applied Health Genetics at Plymouth University. She trained as a nurse and midwife in Australia, and her interest in genetics began in Melbourne when she worked in a foetal diagnostic unit, meeting many couples who were carriers of thalassaemia. In 1989, after moving to the United Kingdom (UK), she began working in specialist genetics and is a registered genetic counsellor.

In 2000, after completing her PhD on the value of genetic counselling for families, she moved to an academic role. She has a long history of providing education to improve the competence in genetic healthcare in a wide range of health professionals within and beyond Europe. Her special interest has been to foster development of counselling skills for health professionals working in a genetics context.

Heather's research, resulting in over 170 peer-reviewed papers, has focussed on improvement of health services for families with genetic conditions, particularly in the field of prenatal genetic testing and screening, and development of professional competence in genetics. She was a partner in the EuroGentest project and led development of European clinical guidelines for presymptomatic, prenatal and direct to consumer testing. She was the project leader for the EU-funded Gen-Equip project (2014–2017) to provide genetics education for primary care professionals.

In the UK, Heather was a Chair of the Association of Genetic Nurses and Counsellors for 6 years and helped design the registration system for genetic nurses and counsellors there. She is a past President of the International Society of Nurses in Genetics.

Heather joined the Education Committee of the ESHG in 2004 and was elected to the ESHG Council in 2010. She led the work to establish standards of education and practice for genetic nurses and genetic counsellors in Europe. She was the inaugural chair of the European Board of Medical Genetics.