



ESHG

Ad Hoc Genetic Nurse and Counsellor Accreditation Committee

Report- May 2010

General

The network of genetic nurse and counsellor members currently stands at 114 members from 19 countries. The website (<http://engnc.org/>) is maintained so that members can obtain updates on our activities. Our thanks to Vigdis Stefansdottir, who has contributed her time again this year to maintain the website.

Standards of Education and Professional Practice

The main objective for this year was to progress the work on setting standards of education and professional practice for genetic nurses and counsellors in Europe and we have made substantial progress. After preparing a draft set of standards through the use of electronic communication, we used funding from the ESHG to have a meeting to refine the standards. In November, 2009, 14 participants from 11 countries met in Paris for a long day meeting to prepare the document for dissemination to the entire group. The ESHG funding for our committee covered travel costs for the participants plus one night accommodation and meals, but we were able to use a meeting venue arranged free of charge by genetic counsellors in Paris, and we are grateful to those colleagues for enabling us to use the venue. We finalised the draft and the membership of the network then voted overwhelmingly to approve the standards.

Following approval by the membership of the network, we sent the document to the national genetic nurse or genetic counsellor societies in Europe. It is important that the standards are commensurate with those of individual national professional groups. We have had very positive feedback from the following:

Dutch Association of Genetic Counsellors
French Association of Genetic Counsellors
Norwegian Association of Genetic Counsellors
Association of Genetic Nurses and Counsellors (UK)

All the organisations listed above have approved the standards, with some minor suggested changes that we will discuss in Gothenburg. We are awaiting comments from the Swedish Genetic Counsellor Association.

Our plan is to submit the standards at the ESHG conference to ask the ESHG Board to comment upon them and to eventually send them to the relevant national genetics societies.

Activities at the ESHG/EMPAG conference, Gothenburg, 2010

As there are many countries in which the number of genetic nurses and counsellors is very small, the ESHG/EMPAG meeting is an important focus for networking, as well as education, for genetic nurses and counsellors. However, many have difficulties obtaining funding to attend.

We invited members to submit an application for a Fellowship to attend the conference. All applicants had to submit an abstract (this was intended to encourage them to disseminate good practice). The standard of the applications was very high and we awarded eight Fellowships. Those awarded a fellowship were: Clara Serra, Viviane Cina, Rebecca Pestoff, Yurdugal Erdem, Nina Bosch, Beppy Caanen, Cristophe Cordier, Ramona Moldovan.

The grant was also used to fund a lunchtime meeting on Saturday 12 June from 1100hrs – 1300hrs. At this lunch we will discuss the Professional and Educational standards document and have a guest speaker.

We wish to thank Genzyme for an unrestricted grant that has enabled us to fund the Fellowships and lunchtime educational meeting.

Our workshop on the topic 'Embedding genetic counsellors into clinical genetics in Europe' will take place at the EMPAG meeting on Sunday 13 from 1500-1630hrs.

Thanks

We sincerely thank the ESHG for all the support we have received to carry out this work in the past year. In particular, we greatly appreciate the advice provided by Jerome del Picchia when we sailed into unfamiliar waters.

Heather Skirton and Marie-Antoinette Voelckel.