

Joint UEMS / ESHG Clinical Genetics Workshop on Recognition and Education

Held at UEMS headquarters, 20 Avenue de la Couronne, Brussels
on Wednesday January 20th 2010.

Participants:

MJC committee

- Ulf Kristoffersson (MJC Chair)
- Helen Kingston (MJC Secretary)
- Bernard Maillet (UEMS Secretary General)
- Flemming Skovby (Paediatric Section representative)

ESHG workshop participants / national representatives

- Milan Macek (Czech Republic)
- Robert Newton (UK National Genetics Education Centre)
- Feliciano Ramos (Spain)
- Bela Melegh (Hungary)
- Cristina Rusu (Romania)
- Eleni Frysira (Greece)
- Fred Petrij (Netherlands)
- Alessandra Renieri (Italy)

Introduction: Ulf Kristoffersson

Participants were welcomed by Ulf Kristoffersson, who outlined the establishment and remit of the UEMS Clinical Genetics MJC. When the Specialty achieves recognition and is included in the EU Directive, it will be possible to establish a Clinical Genetics Section within UEMS. It is, however, currently possible for the MJC to establish an advisory Board consisting of representatives from each National Genetic Society.

Status of EU Recognition for Clinical Genetics: Milan Macek

Summary:

The EU Directive 2005/36/EC on recognition of professional qualifications does not include genetics. Although clinical/medical genetics fulfilled the required criteria in 1997, the opportunity for inclusion was missed at that stage. Clinical/medical genetics is recognised as a primary specialty in 22 of the 27 EU member states and as a sub-specialty in Hungary. Recognition is underway in Spain and Belgium but there is no recognition in Greece or Luxemburg (or Cyprus) currently. Lack of recognition posed a serious threat to clinical genetic services in the Czech Republic and Romania, shortly after enlargement of the EU in 2004, when their respective lists of national specialties were compared against those present in the current version of the Directive.

The EU Council Recommendation on Rare Diseases, however, highlighted the importance of the role of genetics, indicating the need for specialist medical training in genetics and providing a justification for "cross-border care" in the clinical genetics, thereby establishing a rationale for its inclusion into the EU Directive 2005/36/EC. European rare disease patient support groups, organised within Eurordis, presented their book "The Voice of 12,000 Patients" at the Rare Disease Day in 2009, supporting the role of genetics in diagnosis and management, based on figures highlighting general under-diagnosis of rare diseases in EU27.

In early 2009, the French Minister of Health made a request to the EC DG Internal Market and Services, for inclusion of Medical Genetics in the Directive. During the Czech EU Council presidency, Milan Macek and the Czech Ministry of Health followed up this initial request and pressed further for recognition. Legal dossiers were collected for all EU/EEA member states that recognised

clinical/medical genetics nationally, together with their national postgraduate curricula, which were found to be in compliance with the consensus Curriculum endorsed by UEMS and ESHG (setting out a 4 year specialist training programme as a minimum standard for postgraduate training in clinical genetics). These, along with support letters and a joint petition from National Human Genetic Society Presidents, were presented to the EC and have been posted on a dedicated section of the ESHG website.

Milan Macek defended inclusion of clinical genetics in the Directive at a meeting in Brussels on October 22nd 2009. Lobbying and support from national presidents of clinical / medical genetics societies was crucial to obtain official Member State endorsements for the inclusion of the specialty in the Directive. All collected documents were presented to the Committee for the Recognition of Professional Qualifications and the results of initial voting, based on a 4-year minimum length of specialty training and official EU Member State endorsements, are expected to be published prior to their next meeting, with the final vote taking place between March and June 2010. If the required number of votes set by the EU Qualified Majority voting scheme is achieved, the specialty will be eligible for inclusion in the Directive when it is amended in 2012.

Genetics Education for Specialists and Non-Specialists – UK experience: Robert Newton

Summary:

The UK National Genetics Education and Development Centre (UK NGEDC) envisages genetics education as a continuum, starting in pre-registration medical education and continuing throughout the post-registration period as part of both general professional training and specialist training. At each stage, the core genetic concepts that must be addressed need to be identified and appropriately assessed. In the UK, learning outcomes for medical students have been identified, endorsed by the Joint Committee on Medical Genetics and included in the General Medical Council's recommendations for medical training, although content of the undergraduate curriculum is determined by individual medical schools. Clinical skills are incorporated into the first two years of post-graduate clinical training (foundation years 1 and 2). A generic curriculum is followed during the subsequent two years of core medical training, after which trainees can apply to undertake specialist genetic training of 4 years duration to become certified and included on the specialist register as a clinical geneticist.

The need for genetic training in other medical specialties in the UK has been determined by undertaking a needs assessment involving Dermatology, Neurology and Cardiology, using a modified Delphi technique to achieve consensus on training requirements. This has allowed the relevant Specialty Training Committees to start incorporating specialty-specific learning outcomes in genetics into their curricula.

Genetics education also comprises an important part of training for General Practice. The UK NGEDC has produced a report outlining genetic competencies required for primary care practice. These findings have now been incorporated into the 'Genetics in Primary Care' curriculum statement produced by the Royal College of General Practitioners. Learning outcomes reflect the need to identify patients with, or at risk of, genetic disease, understand clinical management and communicate genetic information. Assessment involves applied knowledge tests (multiple choice exams), clinical skills assessment (OSCE style exams) and work place based assessment (portfolio of experience). Online learning resources are being developed with opportunities for self-assessment and reflection.

Further information: 'Learning outcomes in genetics: a continuum of education for medical practitioners' and 'UK Workforce Competencies for Genetics in Clinical Practice for Non-Genetics Healthcare Staff – The Patient Pathway' www.geneticseducation.nhs.uk

Group Discussion

There was discussion about the current length of national training programmes. Specialist training is 4 years in many countries, but 5 years in Germany, Poland, Greece, Italy, Sweden and Norway. However, some of the specialty training programmes include time spent in other medical specialties. In addition, the length of medical school training, the length of post-registration general medical training required before entry into the specialty and the length of genetic training within the specialty training period also vary. For example, The Swedish 5 year specialist training programme includes one year of non-genetic medical training whereas the 4 year UK specialist training programme is entirely genetic, but preceded by 4 years post graduation general medical training.

The problems arising as a consequence of genetic services being provided by non-specialists in some EU countries were highlighted as a major concern. This is particularly an issue when patients are seen and counselled by non-medically trained individuals. It was suggested that a forum of medical doctors with special interests and expertise in genetics might be established as the precursor of a "specialist" society that could promote good practice and set standards prior to formal recognition of the specialty.

There was also discussion concerning different responsibilities for issuing laboratory reports between different countries. In some countries this is the responsibility of clinicians. In other countries, where there are well established training programmes for non-medical clinical scientists, this is the remit of scientists. The UK and Dutch representatives could not envisage this practice changing in their respective countries, despite UEMS support for reporting to be done by clinicians.

There was further discussion regarding the need to establish a curriculum and professional recognition for non-medical geneticists, both laboratory and clinical. Currently an ESHG sub-committee is working on this issue and might benefit from using a similar approach to gathering information to that used for EU Specialty recognition. The Clinical Genetics MJC, on behalf of UEMS, could provide support by endorsing curricula developed for non-medical geneticists, as well as the genetic elements in the curricula of non-genetic medical specialists. Support could also be requested from other UEMS Sections, such as Biopathology. It was noted that in terms of training, one issue is to distinguish between the different levels of competence required for the type of genetic counselling provided by specialists, from that provided by non-specialists as part of normal practice. Another issue is to distinguish between accredited and non-accredited private laboratories and determine their methods of licensing.

Milan Macek reported that ESHG plans to obtain data on the number of (WTE) medical and non-medical geneticists and trainees across Europe and the number of genetic centres providing specialist medical and laboratory services.