

Minutes of the 3rd Meeting of National Human Genetics Societies (NHGSs)

During the ESHG Annual Meeting

Monday 18 June 2007 11.15 to 13.15, Nice Acropolis

1. Welcome and Introduction

There were some 50 participants present (exact number not clear as some came late, some left early).

ESHG President Pier Franco Pignatti (Italy) opened the meeting by telling, that its main aim is to learn to know each other and improve collaboration. As a tool for this, he suggested that everybody would send updated information on the NHGS's website address as well as the date of the next national meeting to the Executive Officer of ESHG Jerome del Picchia (jdp(at)medacad.org). He also asked for ideas to improve these meetings in the future.

An introductory round took place; there were representatives from at least the following countries; France, Estonia, Russia, Italy, Greece, UK, Croatia, Israel, Slovakia, Czech republic, Armenia, Finland, Turkey, Denmark, Belgium, Switzerland, Spain, Latvia, Lithuania, Moldova, Serbia, Hungary, Poland, Slovenia, Ireland, Portugal, Germany, the Netherlands, Romania, Malta, Macedonia, Cyprus, Norway. A list of representatives was circulated during the meeting.

2. Report of ESHG activities 2006-2007

Vice-President John Burn (UK) stressed the importance of collaboration as HGSs are stronger together: there are only some 1200-1300 while there are more than 10 000 members in all the European NHGSs together.

ESHG's goals for the coming years, in addition to organizing the top quality ESHG Conferences, is to support various professional groups in genetics to achieve specialties accepted on European level. For that, ESHG has started three new sub-committees for Education Committee; these are the sub-committee for the specialty in clin/med genetics (chair Ulf Kristoffersson), sub-committee for the specialty for nurses/counsellors (chair to be decided), and sub-committee for specialty for laboratory geneticists (chair to be decided).

During 2008, combined membership in BSHG and ESHG will possibly be tried to simplify collection of membership fees.

Jerome del Picchia will start to work part time as executive Officer of ESHG. One of his tasks will be to develop ESHG website and for that, NHGSs were asked to give ideas and contributions. For instance, a links from ESHG website to each of the NHGS's websites could be created. In addition, Executive Officer could help smaller NHGSs in creating websites. These different options will be discussed between ESHG and NHGSs during 2007-2008.

3. Quality Assurance (QAu) for genetic testing, a QAu-database, and laboratory accreditation in Europe

Els Dequeker (Belgium) (and Mike Morris, Switzerland) explained that, according to the Eurogentest data, only about half of all European genetic laboratories participate in EQA-programs and only 18% have accreditation, while many report themselves as being underway towards accreditation. They told about a coming database where the

accreditation status of any laboratory can be seen (now available on Eurogentest or Orphanet websites).

It should be noted by all, that a recent OECD guideline “Principles and best practices for quality assurance of molecular genetic testing” specifically stresses the importance of accreditation or equivalent quality label for genetic testing laboratories.

4. Report on the questionnaires received from the NHGSs, and proposals on how to increase ties among NHGSs and the ESHG

A survey has recently been performed among NHGSs, Pier Franco Pignatti presented the preliminary results.

The survey had collected data from 36 societies (no contact address available for 7 countries), which represented mainly human (18) or medical (13) societies. The societies have altogether over 10 000 members and have 0,5 – 9 yearly meetings with altogether nearly 8000 participants.

5. Medical/Clinical Genetics recognition as a EU Specialty: draft guidelines and collaboration with UEMS

Minutes from a recent meeting of Multidisciplinary Joint Committee of UEMS, in clinical genetics, and draft of the core competences in clinical/medical genetics had been distributed to the participants preliminarily.

Ulf Kristoffersson (Sweden) explained that UEMS (European Union of medical Specialists) started this Multidisciplinary Committee to promote clinical/medical genetics to be an EU specialty. One part of this is to agree about the requirement for the specialty, defined in the draft core competences. Ulf Kristoffersson asked the participants to comment/agree on the draft by September 2007.

If agreeing about the training program becomes difficult, then another way to get clinical/medical genetics to be an EU specialty is to have 10 EU health ministers to suggest this, which may need some lobbying. The fact that the OECD guidelines mentions medical genetics as a specialty covering both laboratory and clinical aspects strongly supports this endeavour.

6. Training and education needed for genetic counselling : can we have one model for Europe ?

Helena Kääriäinen (Finland) told that, at present, training and education in genetic counselling mainly takes place on national level, in the clinical training of different genetic professionals. EGF courses on genetic counselling are an example of training on European level. EGF is aiming at changing their focus from training genetic counsellors to training the trainers. Eurogentest is, as one of its tasks, creating guidelines for genetic counselling as well as instruments for assessing the quality of genetic counselling, which will have a role in forming the education in genetic counselling. In this, the help of NHGSs is greatly appreciated.

7. Core competences in genetics for health professionals in Europe

Domenico Coviello (Italy) told that Education Committee, in collaboration with Eurogentest, has prepared draft document on the core competences for different professionals involved in genetics in health care. The document is available on ESHG website. Comments to improve the documents are welcomed.

8. European exchange of candidates for medical genetics specialization

Albert Schinzel (Switzerland) had made a proposal to stimulate European exchange of candidates for medical genetics specialization (written proposal was distributed to participants). This detailed proposal was discussed in depth but no decision about the action to take was made. Funding was seen as a problem, possible some existing programs (Erasmus, Socrates?) could be used. John Burn believed that Peter Farndon (The National Genetics Education and Development Centre, Birmingham, UK) may have similar plans and he suggested collaboration.

Domenico Coviello mentioned, that this problem is partly solved by the EGF plan to start e-learning courses.

9. General discussion and Conclusions

In general discussion the work towards medical genetics as an EU specialty was seen as a priority.

Several thoughts were reflected together. It was suggested that new ways to collaborate (e-mail lists, internet communication tools) were suggested. Some European-wide ideas to promote genetics were suggested: Watson-exhibition going around Europe could visit all countries/societies, there could be an European DNA-day and/or a "rare day" yearly or with longer intervals. It might be useful for the NHGSs to get a list of their citizens of their countries who have attended ESHG Conference. This could be done if people when registering gave their permission to this.

10. Closing of the meeting

At the end of the meeting a photograph was taken to document this meeting. The photo will be sent to participants, to be shown also in the local NHGSs meetings.

The next ESHG/NHGSs meeting was scheduled during the ESHG conference 2008 in Barcelona.