2nd Meeting of the Presidents of National Human Genetics Societies RAI Congress Center, Amsterdam, Monday 8th May 2006 at 11.15-13.15.

1) Welcome and introduction

Professor Pier-Franco Pignatti welcomed the participants to the 2nd meeting of NHGS the aim of which is to lead ESHG and the NHGS to move closer to each other. It was noted that the Agenda and invitation had been sent in good time in March 2006.

2) Self presentation of the participants

Participants (about 40, some were coming late and others leaving early) shortly presented themselves. List of participants was as follows:

Representatives of ESHG:

John Burn, President of ESHG

Andres Metspalu, Vice-President of ESHG Pier-Franco Pignatti, President-Elect of ESHG

Helena Kääriäinen, Secretary General of ESHG

Andrew Read, Treasurer, ESHG

Domenico Coviello, Chair of Education Committee, ESHG

Heather Skirton, Representative of Education Committee, ESHG

Ulf Kristoffersson, Ad Hoc Committee on the European Specialty in Medical/Clinical genetics

Representative of Eurogentest:

Gert Matthijs

Representatives of NHGS

Austria: Hans-Christoph Duba

Belgium: Miikka Vikkula Croatia: Ingeborg Barisic Czech Republic: Peter Goetz

Denmark: Kirsten Rasmussen Estonia: Andres Metspalu Finland: Minna Pöyhönen France: Segolene Aymee

Germany: André Reis

Greece: Zoe Kosmaidou-Aravidou

Hungary: G. Kosztolanyi

Italy: Franca Dagna-Bricarelli

Latvia: Natalia Promina Lithuania: Vaidutis Kucinskas

Macedonia: Diyaha Plaseska-Karanfilska

Norway: Geir Julius Braathen Poland: Tadeusz Mazurkzak

Portugal: Isabel Carreira, Ana Maria Fortuna

Romania: Cristina Skrypnyk Serbia-Montenegro: Dragica Radojkovic

Slovenia: Damjan Glavac, Borut Peterlin

Spain: Feliciano Ramos Sweden: Thoas Fioretos Switzerland: Albert Schinzel

The Netherlands: Martin Breuning, Peter Heutink, Hans Scheffer

Turkey: Tayfun Ozcelik United Kingdom: Andrew Read

3) The ESHG activities

President John Burn shortly discussed the challenge that the widening scope in genetics is creating to ESHG and the NSHG. For these challenges, it is especially important that ESHG and NHGS find ways to collaborate.

For that, it was suggested (as it was already suggested during the last meeting on 12.9.2005) that each NHGS would nominate a ESHG liaison person for 3-5 years. Possibly, this same person could also be the liaison to the ESHG Education Committee. This would be useful as the Presidents are usually rotating more quickly. It was suggested that, if the ESHG Board agrees, these individuals would form ESHG's Committee of European Human Genetic Societies. Also, ESHG Board should decide who would chair this committee etc.

4) Proposal for linking the national societies' websites to the ESHG website
Helena Kääriäinen suggested that the NHGS would allow ESHG to put to its website a link to their
websites. If this is not done, it easily happens that the information about NHGS on the ESHG
website is outdated. In addition, information about most of the NHGS is totally lacking on ESHG
website. It was decided that the contact person of ESHG website Paula Koivumäki
(paula.koivumaki@utu.fi) will try to organize the links and update the list of contact information of
NSHGS. A minimal common form in English that should appear in each society website kindly
prepared by Mireille Claustres was distributed and approved.

5) Medical/Clinical Genetics as a EU Specialty: an update

Ulf Kristoffersson explained that at present 19/25 EU countries have medical/clinical genetics as a specialty for medical doctors. There are two ways to get it as a EU specialty: either health ministers of all EU countries should ask for it (which is unrealistic) or it has to be dealt with via UEMS. Medical geneticists are not members of UEMS as the specialty is not on the 1994 list of EU specialties. However, Ulf Kristoffersson has met with members of UEMS, especially representatives of paediatricians and gynaecologists, which has led those representatives to suggest to UEMS that a committee be formed to start to work for approval of the specialty. Ulf Kristoffersson, Dian Donnai and Didier Lacombe have made a suggestion for the core curriculum for the specialty; ESHG Board has accepted it and it has been sent to UEMS.

If clinical/medical genetics, with the support of UEMS, will become a EU specialty, a governing body ("College of Clinical geneticists") is needed. Selecting representatives to it should start and each country should suggest a representative.

President John Burn promised that he will take promoting this specialty as one of his main goals during his year of presidency.

6) Eurogentest activities: an update

Gert Matthijs gave a short update on Eurogenetst activities and invited all the representatives of NHGS to visit Eurogentest website for more detailed information.

7) Collecting information on courses in genetics in Europe to set up a common database

Domenico Coviello presented this plan which is one of the goals of ESHG Education Committee. An idea has been to collaborate with ASHG in this. He invited everybody to report possible coming courses/training opportunities to Education Committee.

8) Definition of minimum core competences in clinical practice, for geneticists and non-medical professionals.

Heather Skirton presented this plan. The idea is to start from the needs and expectations of patients. These needs have to be translated into practice by training geneticists, clinicians on other fields of medicine and non medical professionals.

9) Next meetings of NSHG

It was decided that the representatives of ESHG and NHGS will meet at least once a year during ESHG's yearly Conference. In addition, there could be letters circulated by email, a discussion board created in the web etc. It was also discussed whether a meeting during ASHG meetings would be useful, but at least for 2006 such a meeting was not planned.