

Meeting of Representatives of European Society of Human Genetics (ESHG) and
Presidents/Delegates of European National Human Genetic Societies (NHGS)

Hotel Sheraton, Brussels Airport, September 12, 2005

Minutes

1. Present in the meeting:

Belgian Society of Human Genetics, Sara Seneca (treasurer)
British Society of Human Genetics, Andrew Read (delegate)
Cyprus Society of Human Genetics, Kyroula Christodoulou (president)
Croatian Society of Human Genetics, Ivo Baric (president)
Czech Society of Medical Genetics, Lenka Foretova (vice-president)
Danish Society of Medical Genetics, Kirsten Rasmussen (president)
Estonian Society of Human Genetics, Tiina Talvik (president)
Finnish Society of Medical Genetics, Minna Poyhonen (president)
French Society of Human Genetics, Mireille Claustres (vice-president)
German Society of Human Genetics, Peter Propping (delegate)
Hellenic Association of Medical Geneticists, Zoe Kosmaidou-Aravidou (president)
Hungarian Society of Human Genetics, Istvan Rasko (president)
Irish Society of Human Genetics, Andrew Green (secretary)
Italian Society of Human Genetics, Pier Franco Pignatti (president)
Lithuanian Society of Human Genetics, Vaidutis Kucinskas (president)
The Netherlands Society of Clinical Genetics, I M van Langen (vice-president)
Norwegian Society of Medical Genetics, Gunnar Houge (president)
Polish Society of Human Genetics, Tadeusz Mazurczak (president)
Portuguese Society of Human Genetics, José Carlos Ferreira MD (secretary)
Russian Society of Medical Genetics, Evgeny K. Ginter (president)
Spanish Association of Human Genetics, Feliciano J. Ramos (president)
Swedish Society of Medical Genetics, Ulf Kristoffersson (delegate)
Swiss Society of Medical Genetics, Albert Schinzel (delegate)

European Society of Human Genetics, Andres Metspalu (president)
European Society of Human Genetics, Helena Kääriäinen (secretary general)
European Society of Human Genetics, Domenico Coviello (chair Education Committee)
EUROGENTEST, Jean-Jacques Cassiman (coordinator)

2. Professor Andres Metspalu, President of ESHG opened the meeting explaining that this meeting had been planned by the Board of European Society of Human Genetics (ESHG) in its last meeting in Prague, May 2005. The intention was to start a closer collaboration between ESHG and National Human Genetic Societies (NHGS). In his opening speech, Professor Metspalu also asked every NHGS to suggest some 2-3 names of active geneticists in the country to be possibly integrated to the Board of ESHG or its Committees. These could be sent to helena.kaariainen@utu.fi

3. The participants shortly introduced themselves and their Society. The European NHGSs turned out to be very diverse: old or new, very large (nearly 2000 members) or very small etc. In addition it appeared that in many countries there are several different human/clinical etc. genetic societies and not always a functioning umbrella society.
4. Professor Pier Franco Pignatti explained the ways used in contacting the NHGSs. He had approached 33 NHGSs according to address list that he had got from Eurogenetest. The following countries did not respond: Latvia, Luxembourg, Slovakia, Bulgaria, Romania, Serbia. In addition, he never got any address from the following: Albania, Belarus, Bosnia-Herzegovina, Iceland, Macedonia, Moldova, Ukraine. If anyone knows contact routes to any of these NHGSs, please send them to [<pierfranco.pignatti@univr.it>](mailto:pierfranco.pignatti@univr.it) or helena.kaariainen@utu.fi.
5. Professor Pignatti drafted the possible levels/ways of cooperation between ESHG and NHGSs. They were at least:
 - a. On EU level:
 - i. EU Med/Clin G specialty (Kristofferson)
 - ii. EU HG education (Coviello)
 - iii. EU genetic testing (Eurogenetest, Cassiman)
 - iv. EU HG research
 - b. From the NHGSs' point of view:
 - i. The hierarchy between possible many genetic societies in the context of European/foreign contacts
 - ii. to get to know each other
 - iii. To interact and coordinate some activities
 - iv. To participate actively in ESHG
 - c. From ESHG's point of view
 - i. To relation more with NHGSs
 - ii. To get wider representation to ESHG Committees (Scientific Program, Annual Meetings, Public & Professional Policy, Education, Patenting & Licencing, Publications)
 - iii. To get more readers/authors to European Journal on Human Genetics (EJHG)
 - iv. To evaluate the for genetic courses and other European education
 - v. To get input and feedback for the Website and Newsletter
6. Professor Pignatti brought up the idea of a Federation of NHGSs but this was not further discussed. It was suggested that ESHG should have more contact also with European genetic societies specially focusing on chromosomes. One of the main aims of collaboration between ESHG and NHGSs could be creating a reliable database on contact persons to each of those societies. One possibility would be to join the membership fees.
7. It was decided that next meeting of presidents/delegates of NHGSs will be held during ESHG Conference in Amsterdam 6-9.May, 2006.
8. Ulf Kristoffersson (Chair of Ad Hoc Committee of ESHG on clinical/medical genetics as a European specialty) explained the current state of negotiations. The Committee had prepared a draft "Description of Clinical Genetics as a medical specialty in EU; aims and objectives for specialist training" that had been sent to the participants in advance. It was noted that only two EU-countries do not have the specialty: Spain and Greece. There was

much discussion on the name (clinical/medical) and on the need for a specialty for non-medical geneticists. It was agreed, that the question of the name of the specialty could be left to member states. Also, it became understood that medical specialty is a separate issue and has to be dealt separately. Simultaneously, Lina Florentin (former ESHG Board member; (lflorentin@leto.gr)) is preparing an approach to the specialty of non-medical geneticists. As the issue is ongoing, Ulf Kristoffersson invited the participants to contact him to be updated on possible progress.

9. Professor Jean-Jacques Cassiman introduced EUROAGENTEST which is a European network for genetic test development, harmonization, validation and standardization of services. It consists of 6 units with expertise on quality management and accreditation / certification of genetic testing (Unit 1), information sources and bioinformatic tools (Unit 2), clinical genetics, community genetics and public health (Unit 3), ethical, legal and social policy issues (Unit 4) research and emerging technologies and IPR issues (Unit 5) and education (Unit 6). Especially, the quality of the testing methods was considered important and the quality control in case of CF was seen as a positive example. According to Jean-Jacques Cassiman, similar quality control to several rare diseases may be impossible in practice but instead, quality control of methods (i.e. sequencing) may be developed. The participant of the meeting and the members of their societies were invited to visit EUROAGENTEST website (www.eurogenetst.org) and contact the Unit leaders for further collaboration if interested.
10. Helena Kääriäinen (from Unit 3) told that a survey investigating national legislation, guidelines and practices concerning genetic counselling and some other issues related to genetic testing was just finalized and would be sent out to the representatives of NHGSs in a couple of weeks.
11. Domenico Coviello introduced the partly shared goals of the Education Committee of ESHG and Unit 6 of EUROAGENTEST. Continuing education of different professionals involved in genetics as well as of public education could be promoted by European collaboration. He introduced the main goals of ESHG Education Committee as:
 - a. establish the network of national coordinators
 - b. collect existing education material: courses, syllabus, written information material, e-learning initiatives
 - c. prepare a background paper describing the state of art of genetic education to help to evaluate the material collected
 - d. convene a meeting on 10/11 December in Leuven, with representatives from patients, professional, and other EC projects/networks, to:
 - e. evaluate the existing material
 - f. identify needs at the different levels
 - g. agree on core competence to develop a basic framework
 - h. outline objective for the next year
12. Helena Kääriäinen introduced ESHG website (www.eshg.org) and asked for ideas for collaboration with NHGSs. They could be:
 - a. Names of the contact persons of national societies on ESHG website?
 - b. Links to the websites of national societies (at present 8 links)?
 - c. News from the national societies on ESHG website?
 - d. News from ESHG on the national societies website? These ideas were discussed.

13. On a final round the participant brought up several important issues, many of which were not discussed in detail these were
- a. How to deal with already existing subspecialties in the discussion of medical specialties?
 - b. Which would be ways to increase collaboration in research?
 - c. Every (yearly?) meeting of ESHG and NHGSs in the future could have one specific topic
 - d. Participants were reminded of ECARUCA (European Cytogeneticists Association Register of Unbalanced Chromosome Aberrations) and a similar idea of a database of (extremely) rare monogenic diseases was brought up.
 - e. The collaboration could be extended to other Mediterranean countries.
 - f. Some general principles for pre-graduate education should also be developed.
 - g. Idea of European definition of core set of genetic services was brought up.
 - h. It was suggested that the liaison members would be active members other than presidents of NHGSs as these are presidents usually only for a very short time.
 - i. NHGSs could be used to spread the information of ESHG, ESHG conferences etc.
 - j. Simultaneously with thinking about uniform quality etc, the diversity of Europe should be respected.
 - k. Sharing criteria and contents of various educational programs could be very useful.
 - l. Two countries in the EU do not have official recognition for the clinical/medical genetics specialty (Spain and Greece)
 - m. The possible integration between ESHG and the NSHG in one body with a single fee for members
14. Finally, it was decided that the participants of this meeting will be the contact persons to NHGSs if no other information comes from the societies. The next ESHG/NHGSs meeting will take place in conjunction with ESHG conference in Amsterdam 2006.

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