



**Minutes from the 5th meeting of the National Human Genetic Societies
Vienna 2009, Monday May 25, 11.15-13.15 - Lounge 7-8**

1. Welcome and Introduction (Pier Franco Pignatti, NHGS liaison)

2. Presentation of participants

32 countries were represented:

Hans-Christoph Duba (president, Austria)
Joris Vermeesch (president, Belgium)
Draga Toncheva (board secretary, Bulgaria)
Ingeborg Barisic (president human genetics society, Croatia)
Nina Canki-Klain (president clinical genetics society, Croatia)
Mario Loizidou (secretary, Cyprus)
Violetta Anastasiadou (president, Cyprus)
Lenka Foretova (vice-president, Czech republic)
Uffe Birk Jensen (vice-president, Denmark)
Andres Metspalu (president, Estonia)
Kristiina Aittomäki (president, Finland)
Dominique Bonneau (president, France)
André Reis (president, Germany)
Manos Paradakis (president, Greece)
Bela Melegh (president, Hungary)
Andrew Green (ESHG representative, Ireland)
Pier-Franco Pignatti (representative, Italy, leader of NHGS meeting, ESHG)
Natalija Pronina (representative, Latvia)
Vaidutis Kucinskas (president, Lithuania)
Dijana Plaseska-Karanfilska (general secretary, Macedonia)
Alex Felice (representative, Malta)
Robert Hofstra (president, the Netherlands)
Torunn Fiskerstrand (vice-president clinical genetics society, Norway)
Michal Witt (board member, Poland)
Ana Maria Fortuna (president, Portugal)
Christina Rusu (vice-president, Romania)
Vera Izhevskaya (general secretary, Russia)
Jelena Milasin (president, Serbia)
Ludevit Kadasi (president, Slovakia)
Damjan Glavac (president, Slovenia)
Borut Peterlin (vice-president, Slovenia)
Feliciano J. Ramos (president, Spain)
Niklas Dahl (president, Sweden)
Albert Schinzel (representative, Switzerland)
Tayfun Özcelik (representative, Turkey)
Rob Elles (chairman, British Society of Human Genetics)
Frances Flinter (president clinical genetics society, U.K.)
Dian Donnai (president, ESHG, UK)
Jean-Jacques Cassiman (past president, ESHG, Belgium)
Milan Macek Jr. (president-elect, ESHG, Czech Republic)
Helena Käärainen (secretary general, ESHG, Finland)
Gunnar Houge (secretary general elect, ESHG, Norway)
Martina Cornel (Chair ESHG PPPC, the Netherlands)
Ulf Kristofferson (chair, UEMS clinical genetics committee, Sweden)
Heather Skirton (counsellors committee, ESHG, UK)
Jacques Beckmann (representative for ESHG lab genetics committee, Switzerland)
Celia Delozier (liaison ESHG-ASHG, USA)
Jerome del Picchia (executive director ESHG, Austria)

3. **ESHG highlights** (Jean Jacques Cassiman, vice president)
Brief presentation of latest news.
4. **ESHG future activities** (Dian Donnai, president)
Stressed ESHG's role as "The voice of human genetics in Europe" and the great importance of the link with the national societies.
Mentioned the role of IFHGS, and that ESHG is ready to take a stronger role therein and in relation to ASHG.
Talked about EGF, its courses, and the continuous support ESHG has given and aims at giving in the future. Peter Farndon, our new EGF liaison officer, will have a close follow-up on the collaboration between ESHG and EGF.
5. **Website / Flash letter / Newsletter** (Helena Kääriäinen, secretary general)
Orientation about our new electronic news letter, and the possibility for the NHGS to present news and information there.
There will be only one paper-newsletter per year.
Mentioned the possibility to make links to other professionals working in genetics in Europe. The ESHG website is currently being redesigned. Jerome del Picchia gave a brief orientation about this.
6. **ESHG courses and ESHG supported courses** (Jerome del Picchia, executive officer)
The new course application form will be ready within a month. The limit on the amount of money that can be used for this was underlined – and that this is just a little support on top of what one can get one self.
For ESHG courses, the support by ESHG will be decided individually for each course. For ESHG supported courses, ESHG gives fellowships and up to 5000 euros for organisational support.
7. **Double membership NHGS and ESHG** (Jerome del Picchia, executive officer)
Orientation given. The U.K. system where ESHG membership costs 35 euros extra on top of the national membership can also be applied to other countries. The system has so far been a great success in the U.K.
Such double membership gives online access to the journal (Eur J Hum Genet), membership access to the ESHG website, and greatly reduced conference rates. Jerome del Picchia will approach the NHGSs interested in this possibility with concrete suggestions on how to achieve this.
8. **EU Council recommendation on European Action in the field of rare diseases: Relation to EU-wide recognition of clinical genetics in Europe** (president-elect, Milan Macek jr.)
The positive recent developments on this issue were outlined, and it is likely that clinical genetics soon will be a new pan-European primary medical speciality.
The importance of lobbying towards national representatives was stressed to ensure UEMS endorsement of the proposal that has been forwarded. In addition, a letter recommending EU recognition of the clinical genetics speciality was circulated for the representatives to sign. A shadow clinical genetic board of the UEMS will be assembled at the next meeting in Gothenburg.
9. **Ad hoc committee for laboratory genetics** (Gunnar Houge, secretary general elect)
Feedback from the members were received, specifically:
 - not to make any difference between MDs and non-MDs in relation to the speciality in laboratory genetics.
 - maybe a member from the ad hoc committee for a speciality in clinical genetics should be included.
 - collect information about current status in the various countries and make databases on e.g. formal requirements and the laboratory specialities already in place.
10. **Ad hoc committee for genetic nurses and counsellors** (Heather Skirton, co-chair)
They have now 82 members across Europe from 24 different countries in the European counsellors network. See www.engnc.org. New members are encouraged to join.
The main work is focused on developing professional standards for this profession within Europe, outline a career path, and work towards the goal that a genetic counsellor is a protected professional name within Europe. The minimum standard for practise should be on

the Masters level.

11. **The DNA-day contest** (Celia DeLozier, co-organizer)

An orientation was given. Piloted in Italy (mainly) in 2008, implemented in 2009, and hopefully even more widespread in 2010. The letter of invitation will hopefully be ready in November for the next year's competition.

12. **Genetic susceptibility testing in common disorders** (Martina Cornel, chair of the PPPC)

A working group document on this is put on the ESHG website for feedback and discussion. Feedback must be received before July-09.

13. **Direct to consumer genetic testing in Europe** (Pascal Borry, Center for Biomedical Ethics and Law, K.U.Leuven)

Various types of genetic test are "randomly" being offered to consumers within Europe, and it is not easy to get an oversight of this. It is also a challenge to get an overview of the national legislations that exist.

Pascal Borry would highly appreciate feedback from the NHGS on the situation in their country.

A document on this issue is being made in the U.K., and this document can be circulated. Unwarranted direct-to-consumer genetic testing is a huge problem in many European countries, and general European recommendation on this issue should be made.

14. **General discussion and conclusions**

It was concluded that these meetings of NHGS representatives at the ESHG conference have been extremely useful for mutual information and feedback. It was decided to continue these meetings, Pier-Franco Pignatti will organize and chair them also in the (near) future.

End of meeting – picture taken.