10th Meeting of the European Human Genetics Societies
Sunday, June 7, 2015, 11.30 – 13.30 hrs
Glasgow - Scottish Exhibition and Conference Centre,

1. Welcome and Introduction
Milan Macek, NHGSs Liaison of ESHG

2. Self-presentation of the meeting participants
Number of countries represented: ??, 1-3 representatives per country.

3. ESHG highlights
Prof. Helena Kääriäinen, President of the ESHG

ESHG will support Eurogentest project for the next two years to re-establish and become self-sustained. A satellite meeting about the quality issues is planned a day before the ESHG conference. All members are welcomed to attend.

ESHG collaborates with EU Commission Expert Group for Rare disease, GA4GH, ASHG, IFHGS, and EURORDIS (started in 2015).

In 2017 we will celebrate a 50th anniversary on ESHG conferences. Members who know old colleagues who were at the first conference might ask them for photos, information or if they would like to participate.

Peter Harper had done 100 interviews with human geneticists. Anyone, who has additional ideas, suggestions, may contact him.

EUCERD made a survey on Cross Boarder Testing. The conclusions were that we should share the expertise and data and that unnecessary administration should be removed. Final paper is expected in autumn.

4. ESHG Public and Professional Policy Committee
Martina C. Cornel, Chair of the Committee

Martina Cornel presented three documents that have recently been published: a document on prioritisation in genetic testing, on whole genome sequencing in newborn screening (developed together with P3G Consortium and HUGO Ethics Committee and also endorsed by Australasian SHG), and on non invasive prenatal testing (NIPT) (prepared with ASHG). Currently, PPPC is working on statements regarding extended carrier screening. The final version is predicted to be available in the second half of the year. The ongoing activities include: postmortem genetics (inter

alia the problem of costs of genetic tests after death when the health care insurance has expired), adoption (dealing with commercial genetic tests in Eastern EU), artificial reproduction (in collaboration with ESHRE) and privacy issues versus data sharing.

5. European Board of Medical Genetics: progress in the past year and plans for 2016
Heather Skirton, Chair of EBMG

EBMG is a "child" of ESHG, but is now not only an independent legal entity, but also economically independent due to income from issuing certificates. 5 genetic nurses + 35 genetic counsellors are now registered in total, in 2014 and 2015. This year registration for clinical laboratory genetics was also opened up, and 259 CLGs from "group I countries" (with a national system) got certificates (!). The Medical section has written an improved curriculum. Special process to deal with complained have been established.

6. Union of European Medical Specialists – Clinical Genetics
Ulf Kristofferson, Division chair of EBMG

UEMS Section of Clinical Genetics (SCG) was formally established in 2013. Altogether 19 countries have appointed delegated to SCG. Spain got specialisation last year but there are still some European countries without specialisation (e.g. Greece, Belgium, Croatia..). In the year 2014 the curriculum has been updated and the future activities involve the development of the European syllabus for training of specialists in clinical genetics and the launch of multidisciplinary Joint Committee with UEMS for Rare Disease.The new president of SCG is Béla Melegh.

7. **Education Committee and the ESHG sponsored courses**
Han Brunner, Past-President and Chair Education Committee

A new education committee was established. Chiar is Han G. Brunner (new course portfolio) and members are Domenico Coviello (pre-meeting public event), Christophe Cordier (DNA day) and Jill Clayton-Smith (educational material).

The course portfolio was expanded: cardio-, cancer-, statistical-, cyto-, and prenatal genetics courses were added. ESHG supports them mainly by fellowships that would allow people from less affluent countries to attend. ESHG ask for the report about the success of the course and about financial matters. A society promotes web-casting of courses but appropriateness regarding the topic would need to be evaluated.

7. DNA Day 2015
Christophe Cordier, ESHG Education Committee

The number of essays is increasing. This year 276 essays were submitted by students from 19 countries (the largest number from Bosnia and Herzegovina). The essays were evaluated by more than 50 experts. The winners are from The Netherlands, Lithuania, and Spain. In some countries (e.g. Italy, Hungary) DNA day is part of the the National Society Meeting which increases the popularity of the event.

8. Guest presentation 1: An international charter for sharing data and **biospecimens: a rare disease imperative'**
Dr Simon Woods, University of Newcastle, UK

RD Connect aim is to create a platform to make RD genomic and other data available. It is connected with patients and patient's organisation and has a very good dialogue with them. The main challenges for rare disease researches are: organisation of scattered data, data sharing, and samples storing in accordance with ethical and scientific standards.

9. Guest presentation 2: Global Alliance for Genomics & Health

John Burn, Newcastle, UK

GA4GH has been founded in 2013 to enable responsible data sharing to improve patients care. One of the current demonstration projects is BRCA Challenge, that aims to develop a database of variants in BRCA1 and BRCA2 pooled from all over the word. The BRCA Challenge should be an exemplar for similar data sharing across the whole Human Variome.