12th Meeting of the European Human Genetics Societies
Sunday, May 28, 2017, 11.00 – 13.00 hrs
Bella Conference Centre,
Copenhagen, Rooms 18-19

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

2. Self-presentation of the meeting participants

49 delegates representing 37 societies from 33 countries

3. ESHG highlights

Olaf Riess, President of the ESHG, gave an overview of the of the activates of the ESHG committees (see also Newsletter)

The society is growing and has members from 77 countries. A proposal for new membership fees was introduced. NHGS may use the possibility for the joined membership for national society and ESHG. We often get request for reduced membership fees. Currently we have many categories for different groups but we are open for suggestions. The new website will shortly be launched. All are requested to give their comments and recommendations. In October/November will be the next call to extend the ERN's. It is important to add our expertise to the new formed ERN's. Currently the ESHG is spread among three countries which creates potential tax tread, therefore we would like to unify it to one country, most likely to Austria, but we are still in the negotiation/exploratory phase. EJHG has the partnership with Springer-Nature. They offered us a development fond to promote/improve the journal. We are open for suggestions!

4. European Board of Medical Genetics (EBMG)
Heather Skirton, Chair of EBMG
Heather gave an overview of EBMG work and progress. The registration fee will be similar for GNGCs and CLGs this year. 69 GNGC are approved so far, 29 applied this year. GNGC also have an "associate system" for registrants from outside Europe. 84 people applied for CLG certification this year, 42 of them need to take an exam. Heather Skirton will retire this year and Angus Clare will be interim Chair until elections next year.

5. DNA Day 2017
Christophe Cordier, ESHG Education Committee DNA Day Coordinator
In total 244 essays were received from 20 countries. Top scoring countries were Turkey, France, and Italy, and they also got the first three prices. For the 2018, we plan to add video contest. All NHGS are invited to encourage students from their countries to write / send essays and to join the assessor team at the next year's

contest.

6. European Union of Medical Specialists (UEMS) – Clinical Genetics
Bela Melegh, Chair UEMS
Bela Melegh presented UEMS, its connections with the CESMA and EACCME and its connections with ESHG and EBMG. It is planned to launch the first medical genetics exam in Milan.

7. ESHG Public and Professional Policy Committee (PPPC)
Martina C. Cornel, Chair of the PPPC
One of the main activities was preparation of the background document and recommendations on gene editing, made together with ESHRE. The document was endorsed on 26-5-2017. There is work going on related to sudden death post-mortem genetic testing, this together with cardiologists and the Brocher foundation. Suggestions for new topics: i) recontacting issues, ii) cascade screening/informing relatives, iii) the "56 ACMG genes", iv) our responsibility to explain the test results from DTC.

8. Education Committee and the ESHG sponsored courses
Han Brunner, Chair Education Committee

9. International Federation of Human Genetics Societies
Helena Kaariainen, ESHG Liaison Officer
The main action of IFHGS has been supporting the ICHG conferences. The next one was will be in 2021 in Capetown. Additional aims were suggested: to increase the number of fellowships, free video courses, student/researcher exchange. All member societies are encouraged to check and update the addresses on the website if needed.

10. How can we improve together the diagnostic testing process?
Els Dequecker
In 2001, the results of EQA (External Quality Assessment) scheme for cystic fibrosis were reviewed and showed that the percentage of the laboratories making errors had fallen progressively. Still today, there are around 5-9% of laboratories categorised as persistent poor performer (PPP), meaning that these laboratories did not successfully participated at least twice in three consecutive years. There is a need for a national advisory board / regulatory board to follow up and implement improvement action for PPP genetic centres.

11. Guest presentation 1: ERN for Rare Congenital malformations and Intellectual Disability (Ithaca)
Jill-Clayton Smith, Manchester
Jill-Clayton Smith presented ERN Ithaca. The aim is to facilitate access for undiagnosed patients, to develop best practice and initiate guideline development where required. 38 centres from 14 member states have joined already and new members will be able to apply in December.

12. Guest presentation 2: RD-Connect.eu project
Ivo Gut, Barcelona
Ivo Gut presented RD-connect, an integrated platform connecting omics data, clinical information, registries, and biobanks for rare disease research. He stressed that genetic tests should be requested from the companies with accreditation.

13. Guest presentation 3: Recorded interviews with human and medical geneticists

Peter Harper, Cardiff

Peter Harper stressed that it is important to record and preserve the history of genetics across the Europe and the world. Geneticists and historians should collaborate with each other. The national societies have to promote this initiative and find at least one person prepared to do the interviews. ESHG can be helpful in facilitating the initiative. The interviews could be archived on the national websites.

List of delegates:

Elena	Abzianidze	Medical Genetics and Epigenetics Society of Georgia	GE
Dodo	Agladze	National Board of Genetics Georgia	GE
Hayane	Akopyan	Ukrainian Association of Medical Genetics & Laboratory Diagnostics	UA
Ingebord	Barisic	Croatian Society of Human Genetics	HR
Lina	Basel	Israelis Society of Medical Genetics	IL
Chiril	Boiciuc	N/A - Moldova	MD
Isabella	Borg	Genetics Group within Malta Colelge of Pathologists	MT
Nina	Canki-Klain	Clinical Genetics Society of Croatia	HR
Adela	Chirita-Emandi	Romanian Society of Medical Genetics	RO
Christophe	Cordier	ESHG	CH
Martina	Cornel	ESHG	NL
Jerome	del Picchia	ESHG	AT
Els	Dequeker	ESHG-EUGT	BE
Kyriakos	Felekkis	Cyprus Society of Human Genetics	CY
Marurizio	Genuardi	Italian Society of Human Genetics	IT
Gabriele	Gillessen-Kaesbach	German Society of Human Genetics	DE
Damjan	Glavac	Slovene Society of Human Genetics	SI
Ivo	Gut	Guest Speaker	ES
Frederik	Hes	Netherlands Society of Clinical Genetics	NL
Gunnar	Houge	ESHG	NO
Veia	Izherskaya	Russian Society of Medical Genetics	RU
Helena	Kääriäinen	International Federation of Human Genetics Societies	FI
Ludevit	Kadasi	Slovak Society of Human Genetics	SK
Peter	Kroisel	Austrian Society of Human Genetics	AT
Ants	Kurg	Estonian Society of Human Genetics	EE
Eka	Kvaratskhelia	Medical Genetics and Epigenetics Society of Georgia	GE
Didier	Lacombe	French Federation of Human Genetics	FR
Luca	Lovrevic	Slovene Society of Human Genetics	SI
Sally Ann	Lynch	Irish Society of Human Genetics	IE
Milan	Macel Jr	Czech Society of Medical Genetics	CZ
Bela	Melegh	UEMS	HU
Olivera	Miljanovic	N/A - Montenegro	ME
William	Newman	British Society of Genetic Medicine	UK
Markus	Nöthen	German Society of Human Genetics	DE
Ivana	Novakovic	Serbian Society of Medical Genetics	RS
Elsebet	Östergaard	Danish Society of Medical Genetics	DK

Christine	Patch	ESHG	UK
Dijana	Plaseska-Karanfilska	Macedonian Society of Human Genetics	MK
Feliciano	Ramos	ESHG	ES
Olaf	Riess	ESHG	DE
Luisa	Romao	Portuguese Society of Human Genetics	PT
Tamara	Sarkisian	Armenian Society of Human Genetics	AM
Heather	Skirton	EBMG	UK
Marta	Szell	Hungarian Society of Human Genetics	HU
Aspasia	Tsezou	Hellenic Association of Medical Geneticists	GR
Kristian	Tveteen	Norwegian Society of Human Genetics	NO
Algiras	Utkus	Lithuanian Society of Human Genetics	LT
Marie-Antoinette	Voelckel	French Association of Genetic Counsellors	FR
Karin	Writzl	ESHG	SI