



FH Patient Advocacy Group Representatives Meeting 21st March 2015 (Sessions 1 & 2) and 22nd March 2015 (Session 3)

Agenda

Day 1 Session 1 : Saturday 21st March, 5.30-8.00 pm

Radisson Blu Hotel, Glasgow

Co-chairs Profs Ray and Catapano

5.30-6.00 pm Arrivals, coffee & refreshments

6.00-6.05 pm **Welcome on behalf of EAS** Prof Catapano

Objectives and outline of the advocacy group meeting Prof Ray

6.05-6.50 pm **Round the World—Current State of Affairs**

5 min presentations from each top line on: the state of patient advocacy in each country, when organisations were started, their reach, their impact: where such organisations are lacking the impact of this absence

UK, Heart UK Ms Jules Payne
Australia Mr Waleed Farid
Brazil Prof Tania Martinez
Taiwan Dr Ta-Chen Su
USA Ms Sue Koob
USA Ms Stacey Lane
Russia Prof Andrey Susekov
South Africa Prof Frederick Raal
South America..... Prof Mario Stoll

6.50-8.00 pm **Panel / Audience Discussion**

Chairs Prof Catapano and Prof Lale Tokgözoğlu

Panelists:

Dr Gunnar Karlsson (Sweden), Ms Margaretha Hamrin (Norway), Ms Michaela Wolf (Germany), Ms Barbara Fletcher (USA), Susanne Greber-Platzer (Austria), Mr Athanasios Pallidis (Greece), Prof Richard Ceska (Czech Republic), Ms Iva Dimova (Bulgaria), Dr Seth Baum (USA), Dr Mario Stoll (Uruguay), Ms Britt Marie Rosell (Sweden), Prof Andre Miserez (Switzerland), Mr Dan Johansen (Norway), Dr Gianpaolo Tibolla (Italy), Prof Paragh György (Hungary), Prof Gustavs Latkovskis (Latvia), Prof Vincent Durlach (France), Ms Marie-Pierre Gabeur (France)

Topics: ~ 20 mins on each

- How might current patient advocacy groups share their experience and knowledge with countries who have yet to develop such organisations across EAS member countries and beyond?
- What lessons can be learnt from successes and failures of patient advocacy in eliciting change from different countries?



- What are the impediments to optimum management of FH patients, and how these may be overcome (either through consensus or through customised approaches)?

8.00-8.30 pm

Buffet Dinner

Day 1 Session 2 : Saturday 21st March, 8.30-9.30 pm

8.30-9.30 pm

Panel / Audience Discussion

Chairs Prof Kausik Ray and Prof Gerald Watts

Panelists:

Prof Michal Vrablík (Czech Republic), Prof Lixin Jiang (China), Prof Joep Defesche (Netherlands), Dr Handrean Soran (UK), Dr Solange Pacheco (Portugal), Ms Gabriele Hanauer-Mader (Austria), Prof Raul Santos (Brazil), Mr Ivan Dimitrov (Bulgaria), Prof Eric Bruckert (France), Ms Kristen Bjorklund-Holven (Norway), Prof Lennart Nilsson (Sweden), Prof Meral Kayikcioglu (Turkey), Dr Masahiro Koseki (Japan), Dr Wong-Rieger Durhane (Canada), Anne Tybjærg-Hansen (Denmark)

Topics ~ 20 mins on each

- How do we raise public/ clinician awareness to the contemporary burden of FH, and the consequences of under-diagnosis or under-treatment?
- How do we encourage primary care physicians in particular to contribute actively to the management of subjects with FH?
- How do we promote a uniform, evidence-based standard of care for FH, including genetic counselling and testing as well as timely referral for specialist advice?

9.30 pm

Close of Day 1 Prof Ray

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Day 2 Sunday 22nd March

SECC Congress Centre, Glasgow

7.40 am

Transfers to Congress centre

8.00-8.15 am

Arrivals at the Congress Centre, coffee & refreshments

Day 2 Session 3 : Sunday 22nd March, 8.15-9.45 am

8.15-8.30 am

Outline of Day 2 and outlining the FHSC Prof Ray

8.30-8.40 am

The European Patient Organization network..... Gunnar Karlsson

8.05-9.40 am

Panel /Audience Discussion

Chairs Prof Ray and Prof Catapano

Panelists

Prof Pedro Mata (Spain), Prof Maciej Banach (Poland), Dr Pablo Corral (Argentina), Prof Olivier Descamps (Belgium), Dr Gersina Rega-Kaun (Austria), Prof Kurt Widhalm (Austria), Prof Petri Kovanen (Finland), Mr Jeremiah Mwangi (Switzerland), Prof Stefano Romeo (Sweden), Dr Anja Vogt (Germany), Dr Lazlo Mark (Hungary), Prof Moses Elisaf (Greece), Prof Mariko Shiba (Japan), Ms Veronique Lemaitre (France), Prof Shizuya Yamashita (Japan), Børge Nordestgaard (Denmark)

Topics ~ 20 mins on each

- How can the EAS work together with different patient advocacy groups to enhance cohesion and co-ordination?
- Who are key stakeholders beyond the patient advocacy groups, academic community and industry that we need to work with and is their prior evidence of successful engagement with for instance governments?
- How can patient advocacy groups help with the dissemination of new data and support the EAS FHSC?

9.40-9.50 am

Wrap up and potential next steps Prof Catapano