



FH Europe

The European FH Patient Network

Annual Network Meeting

**Danubius Hotel, Kárpát u. 62-64,
Budapest, 1133 Hungary**

Saturday, 4 – Sunday, 5 November 2017

PRELIMINARY AGENDA

Day 1

- 12.00 Light lunch
- 12.30 Welcome to all members of the Network by the Chair *Jules Payne*
- Welcome to Hungary by a representative of the Hungarian FH organisation
- 12.40 Introducing the Hungarian association and Hungary's national health system
- 12.50 Annual Report and forward review
- Review of FH Europe activity 2017 (including 'heat map'/FH Awareness Day 24 Sept)
Review of accounts for the financial year *Jules Payne / Gunnar Karlsson*
Governance matters *Jules Payne*
Projected funding for 2017-2018 *Gunnar Karlsson*
Update on register of members and receipt of news items
- 13.45 Introduction to Slovakian and Dutch organisations
Branislav Vohnout, Marlieke Janssen ten Haaf (by video)
- 14.00 Coffee break (with healthy snacks) – arrival of sponsor representatives, Hanover Communications representatives and networking
- 14.20 Welcome and introduction to full meeting
- 14.30 Keynote Presentation I: Optimal Treatment of acute MI in paediatric population.
Professor Belà Merkely
- 15.00 Presentation of policy at national level – policy and awareness-raising training
Hanover Communications (proposed 2 consultants)
Welcome/Introduction & scene-setting (5 mins + 15 mins)
Comparing EU vs national competences in health policy (10 mins)
- 15.30 Dos and Don'ts of effective advocacy
- 16.00 Presentation of the FH Europe Advocacy Toolkit
This presentation to include FH Europe member case studies

*FH Europe 2017 network meeting is supported by an educational grant from
Sanofi Hungary, Amgen Limited, Amryt Pharmaceuticals and Akcea Therapeutics*

- 16.30 Ten minute break to arrange groups
- 16.40 Face-to-face messaging workshop with members *Francesco Fuggetta / Theodora Varkonyi-Weisz / Inese Maurina / Diana Maxwell*
 To “develop a message platform to be used by national member as part of their outreach activities”, to develop messages/activity relating to rebutting statin arguments and ‘fake news’ /advocacy role play
- 17.20 Final questions and answers
- 17.30 Close and finish for the day
- 19.15 Dinner in restaurant VakVarju Restaurant, Budapest, Paulay Ede u. 7, 1061 Hungary
 - presentation has been proposed

Day 2 – Sunday, 6 November 2016

- 9.00 Report on outcome of survey of member organisations on PCSK9 reimbursement as an example of developments in influencing decision-makers on new and innovative treatments across member countries *Gunnar Karlsson*
- 9.20 Evolution of cholesterol management in the light of current (or new) guidelines *Prof György Paragh*
- 9.50 Fourier Data presentation and news from the lipid scientific scene *Theodora Varkonyi-Weisz*
- 10.10 Coffee Break
- 10.40 Collection of any completed travel forms and member organisation registration forms
- 10.45 Report on e-media in member countries *Francesco Fuggetta and Inese Maurina*
- 11.10 Current status of Paediatric and other Registers – differences in systems and possibility of interoperability across national boundaries (educational item followed by discussion)
Jules Payne / Gabriele Hanauer-Mader
- 11.25 Discussion and review of possible organising committee for 2018 network meeting
- 11.45 Any other business
 Location and date of 2018 meeting
 Venue/event feedback form / Meeting close
- 12.00 Light lunch
- Mid-day onwards - Departure of members who are flying out in the early afternoon

Ref: location map for Danubius Hotel Helia in Budapest
<https://www.google.com/maps?daddr=47.52559,19.055563>
 The restaurant VakVarju is a 15 minute walk from the hotel

FH Europe 2017 network meeting is supported by an educational grant from Sanofi Hungary, Amgen Limited, Amryt Pharmaceuticals and Akcea Therapeutics