



FH Europe

The European FH Patient Network

Annual Network Meeting

Hyatt Regency, Paris Charles de Gaulle Airport

Saturday, 3 – Sunday, 4 November 2018

AGENDA

Day 1

12.00 Light lunch

12.30 Welcome to all members of the Network by the Chair *Jules Payne*

12.40 Welcome to Paris and introduction to the French association *Professor Vincent Durlach/Veronique*

Lemaitre

12.50 Trustee report for the period ended 28 February 2018 *Jules Payne/Gunnar Karlsson*

Financial status and Projected funding for 2018-2019
FH Europe activity 2018 - 2019
Register of members - Information for the register
FH Europe Organisation, Governance etc.
(How to manage the network and ensure its development)

14.00 Coffee break (with healthy snacks) - arrival of sponsor representatives

14.20 **Welcome and introduction to full meeting**

14:30 Introduction to Turkish and Russian associations
Meral Kayikcioglu, Askar Faskhutdinov

14.45 Keynote Presentation I: Genetics - "How molecular diagnosis may contribute to decipher the phenotypic heterogeneity of hypercholesterolemia"
Alain Carrié,
Paris

15.15 Keynote Presentation II: Paediatric screening
Professor Albert Wiegman, AMC, The Netherlands

15.45 Workshop with members - a demonstration of how to use mobile devices to create high quality videos.
A 2-3 hour demonstration with frontal presentation and workshop in small groups to try the technical devices.
Possibly a complex modular programme offering:
- Facebook (what is important to know, how to position yourself, etc.)
- Do it yourself videos/interviews (short, long, with explanation re video style and suitable length)
- Marketing communication social media
- YouTube channel

If there is sufficient time, additional workshop options are:

- Editing - basic knowledge

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- How to use `Google drive` and why it is important
- Using Twitter
- 17.35 Final questions and answers
- 17.45 Inese Maurina to provide an update on Latvian FH disease code
- 17.55 Close and finish for the day
- 19.15 **Dinner** - restaurant to be confirmed

Day 2 - Sunday, 4 November 2018

- 9.00 'Tour de table' from member associations on highlights of their year (2017-2018)
 - 9.40 Dr Sophie Béliard - "Lessons from the French Familial Hypercholesterolemia Registry: real-life data on the disease".
 - 10.10 Coffee Break
 - 10.40 Collection of any completed travel forms and member organisation registration forms
 - 10.45 Report/presentation relating to rare disorders and in general the benefits of patient-to-patient support
Theodora Varkonyi-Weisz will include a brief presentation on the importance of patient support
 - 11.10 building "Introduction to the work of the European Alliance for Patient Access (EAfPA): effective advocacy to address patient access to approved therapies" *Neil Betteridge*

(This presentation will briefly describe the work of the Alliance, which is the European division of the Global Alliance for Patient Access. It will provide short case studies, from the US and Europe, to illustrate how the Alliance can help raise the voice of physicians and patient groups on policy issues which affect patient access. It will also focus on specific policy issues around cholesterol management in at-risk patients and how a patient group network could have a positive impact on the lives of these patients.)
 - 11.35 Actions for 2019
Possibility of updating the 'heatmap' in 2019
Discussion and review of possible organising committee for 2019 network meeting
 - 11.45 Any other business

Location and date of 2019 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

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