

**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

- 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 “Introduction to the work of the European Alliance for Patient Access (EAfPA): building

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