

FHEF ANNUAL NETWORK MEETING

Together, engaged for change

Vienna, Austria
8 - 10 November 2024

Agenda (vs. 2024.8.15)

Pre-meeting online webinars

(Every Thursday in October, 18.00 - 19.00 CET)

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| 3 October 2024 | <i>HeFH – the latest management updates</i> |
| 10 October 2024 | <i>HoFH – the latest management updates</i> |
| 17 October 2024 | <i>Elevated Lp(a) - the latest management updates</i> |
| 24 October 2024 | <i>FCS – the latest management updates</i> |

8 November (Friday)

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| Friday afternoon
(14.00 - 18.00) | <i>Governance and industry meetings</i>
A governance meeting and an industry round table will take place during the day. |
| Friday evening
(19.00 - 22.00) | <i>A welcome reception with a buffet dinner</i>
In the evening a welcome reception will take place, with a buffet dinner and an 'icebreaker activity' |

9 November (Saturday)

9.00 – 9.15	Welcome and programme overview
9.15 -10.30	Presentations <ul style="list-style-type: none">• A changing global and European environment and implications for FHEF.• Spotlight on excellence – 3 examples of where the network members shine and key learnings.• Getting to know our co-hosts in Austria -where the FH community is growing- key movers and shakers.
10.30 - 11.00	Coffee Break
11.00 - 12.30	Debates <ul style="list-style-type: none">• Can we start to think about testing for FH and Lp(a) simultaneously? What are the pros and cons?• What are the links between FH and diabetes/obesity? Why is it crucial to keep this distinct from the mainstream cholesterol/obesity discourse?• How do we advance the rare lipids agenda, and collaborate more with the wider rare diseases' community? Implications of Clinical Trials/new therapies in the FCS space, new guidelines in HoFH. Briefing for the afternoon session
12.30 – 13.30	Networking Lunch
13.30 – 14.45	Break-out sessions <p>The first part of the afternoon will be devoted to break-out sessions, then a hands-on practical session will take place, building on these and the plenary.</p> <ul style="list-style-type: none">• FH break-out session - Based on PERFECTO and an important strategic question for the project team.• Lp(a) break-out session - Based on the Lp(a) Task Force outputs and an important strategic question.• FCS break-out session - What is our advocacy agenda in the rare disease space – what are the key asks?• HoFH break-out session - The role of patient stories in advocacy and support?
14.45- 15.15	Coffee Break
15.15 - 16.15	Workshops

The second part of the afternoon will focus on the following workshops:

- **Workshop 1: The Ambassadors** – How do we implement the knowledge we have gained to advocate better for our communities. Lessons learned so far.
- **Workshop 2: Network Members' Dialogue** – Exchange on the challenges and successes since the last network meeting – what are the needs and expectations from FH Europe Foundation.
- **Workshop 3: Tips and tricks for successful awareness days** – How can we amplify our voice for lasting impact?
- **Workshop 4: FHEF leadership in EU projects** – Address opportunities for the network to get involved.

16.15 - 16.30 Short break

16.30 - 17.10 **Workshop feedback & wrapping up the day**
A final 40-minute plenary session will provide brief top-level feedback on the discussions and the key ideas emerging from the breakouts and workshops.

17.00 - 19.30 Free time and informal networking

19.30 - 23.00 Gratitude dinner

10 November (Sunday)

9.00 - 9.15 Welcome to the 2nd day and agenda overview

9.15 - 10.00 **Looking back on the last year**
key achievements and looking forward - FHEF's long-term strategy

10.00 - 10.30 **Overview of progress to date on the FHEF long-term strategy**
a phased approach to the organisation's governance, and how the network can get involved.

10.30 - 11.00 **Active Break**

11.00 - 12.00 **2nd part of the session on strategy**
interaction with the participants

12.00- 12.45 **Presentation of the 2025 work plan by the team**

12.45 – 13.00 **Closing remarks and the next annual meeting**

13.00 - **Lunch and goodbyes**