

FHEF ANNUAL NETWORK MEETING

Together, engaged for change

Agenda (vs. 2024.11.05)

Pre-meeting Online series – release Friday, Nov 1st

HeFH – the latest management updates

- *Sabina Salihbasic*, Caregiver for 2 children living with HeFH, Austria,
- *Lena Rosa Hanauer*, Young Patient Ambassador living with HeFH, Austria
- *Prof. Albert Wiegman*, Paediatric cardiologist, specialising in FH, The Netherlands

HoFH – the latest management updates

- *Michelle Watts*, Caregiver for a young patient ambassador living with HoFH, USA
- *Chyrel Lichaa*, Young Patient Ambassador living with HoFH, Lebanon
- *Assoc. Prof. Fotios Barkas*, Internal Medicine, Greece

Elevated Lp(a) - the latest management updates

- *Marie-Therese O'Donohue*, Patient Ambassador living with elevated Lp(a), Switzerland/Ireland
- *Dr Tobias Silberzahn*, Patient Ambassador living with elevated Lp(a), Germany
- *Prof. George Thanassoulis*, Preventative and Genomic Cardiology, Canada

FCS – the latest management updates

- *Elsie Evans*, Patient Ambassador living with HoFH, UK
- *Helga Davidson*, Patient Ambassador living with FCS, UK
- *Assoc. Prof. Antonio Gallo*, Cardiovascular Prevention and Genetic Dyslipidaemias, France

Hybrid event, Vienna, Austria, 8- 10 November 2024

Friday, 8 November

Morning Advisory boards, ancillary meetings, etc (by invitation only)

15:00 – 18:00 **Awareness raising with roasted chestnuts, by FHchol Austria in Mariahilfer Straße**

15:00 – 18:30 FHEF Industry Roundtable meeting (by invitation only)

19:30 – 22:00 Registration and Welcome reception with a buffet dinner (All)

Saturday, 9 November

9:00 – 9:10 **Welcome and programme overview**

- *Nicola Bedlington*, Moderator, Sr Policy Advisor, FH Europe Foundation, Austria
- *Prof. Joanna Lane*, Chairperson, FH Europe Foundation, The Netherlands

9:10 – 9:40 **Setting the stage for Familial Hyperlipidaemias community advocacy**

- **A changing global and European environment and implications for FHEF** (20min)
Magdalena Daccord, CEO, FH Europe Foundation, Switzerland
Sophie Millar, EU Policy and Advocacy Manager, ESC, European Alliance for Cardiovascular Health
Elsie Evans, Ambassador Programme Manager, FH Europe Foundation, UK/South Africa
- **FHchol Austria - Where the Familial Hyperlipidaemias advocacy community is booming** (10min)
Anna Andrea Böhm, Chairwoman, FHchol, Austria

9:40 – 10:15 **Precision Medicine and its implications for the Familial Hyperlipidaemias community**

- *Dr Marius Geantă* Moderator, President InoMed, Trustee FH Europe Foundation, Romania
- **What does Precision Medicine mean to me?** (15min)
Dianne van Leeuwen and *Olivia de Graaf*, Young Patient Ambassadors living with HoFH, The Netherlands interviewed by *Elsie Evans*
- **EP PerMed – Citizen Engagement in Precision Medicine** (10min)
Dr Gianni D'Errico and *Dr Matteo Gentili*, Fondazione Toscana Life Sciences, Italy
- **Precision Medicine – first hand learnings from PERFECTO** (10min)
Dr Marius Geantă, President InoMed, Trustee FH Europe Foundation, Romania

10:15 – 13:00 **DEBATES**

10:15 – 11:00 **Can we start to think about testing for FH and Lp(a) simultaneously? What are the pros and cons?**(45min)

- **Aedan Kaal**, elevated Lp(a) Patient Ambassador, The Netherlands
- **Cheryl Lichaa**, HoFH Patient Ambassador, Lebanon
- **Neil Johnson**, CEO Global Heart Hub, Ireland
- **Prof. Albert Wiegman**, Paediatric Cardiologist, FH Europe Foundation Trustee, The Netherlands
- **Prof. Zanfina Ademi**, Health Economics and Policy Evaluation Research (HEPER) Group, Monash University, Australia (*online*)

11:00 – 11:30 Active Break

11:30 – 12:15 **What are the links between FH and diabetes/obesity? Should the narratives around obesity, diabetes and FH be distinct or connected?** (45min)

- **Verena Kozmann**, elevated Lp(a) Patient Ambassador, Austria
- **Assoc. Prof. Amany Elshorbagy**, Research Fellow in CV Epidemiology, Imperial College, UK
- **Prof. Mafalda Bourbon**, Geneticist, Head of the R&D Unit and CV Research Group, National Ins. Of Health, Portugal
- **Prof. Carine de Beaufort**, Paediatric Diabetes and Endocrinology, Past President of ISPAD, Luxemburg (*online*)
- **Prof. Joanna Lane**, Founder and Managing Director, Stichting HCT, FH Europe Foundation, Chairperson, The Netherlands

12:15 – 13:00 **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.** (45min)

- **Elsie Evans**, HoFH Patient Ambassador, Ambassador Programme Manager, FH Europe Foundation, UK/South Africa
- **Helga Davidson**, FCS Patient Ambassador, UK
- **Dr Ingrid Klingmann**, Chairperson of European Forum for Good Clinical Practice, Belgium
- **François Houyez**, Director of Treatment Information and Access, EURORDIS, France (*tbc-online*)
- **Begonya Nafria Escalera**, Share 4 Rare, Head of Patient Engagement in Research – SJD Barcelona Children's Hospital, Spain
- **Prof. Urh Grošelj**, Metabolic Paediatrician, FH Europe Foundation Scientific Advisor, Slovenia

13:00 – 14:00 Networking Lunch

14:00 – 14:30 **Questions and Answers**

14:30 – 14:45 **Briefing for the afternoon session**

14:45 – 15:45 Break-out sessions

FH break-out session: Based on PERFECTO and an important strategic question for the project team.

- *Magdalena Daccord*, Chief Executive Officer, FH Europe Foundation
- *Dr Marius Geantă*, Founder, Inomed, Romania
- *Assoc. Prof. Andrie Panayiotou*, CTU, Cyprus

Elevated Lp(a) break-out session: Based on the Lp(a) Task Force outputs and an important strategic question.

- *Nicola Bedlington*, Sr Policy Advisor, FH Europe Foundation
- *Marc Rijken*, Patient Ambassador living with elevated Lp(a), The Netherlands
- *Marie-Therese O'Donohue*, Patient Ambassador living with elevated Lp(a), Switzerland/Ireland

FCS break-out session: What is our advocacy agenda in the rare disease space – what are the key asks?

- *Helga Davidson*, Patient Ambassador living with FCS, UK
- *Finn Day-Lewis*, Caregiver to FCS Patient Ambassador, UK
- *Michelle Sibley*, Patient Ambassador living with FCS, UK

HoFH break-out session: The role of patient stories in advocacy and support?

- *Elsie Evans*, Ambassador Programme Manager, UK/South Africa
- *Athanasios Pallidis*, Patient Ambassador living with HoFH, Greece
- *Maria Nassif*, Patient Ambassador living with HoFH, France

15:45– 16:00 **Active Break**

16:00 – 17:00 **Workshops**

Workshop 1: The Ambassadors – How do we implement the knowledge we have gained to advocate better for our communities. Lessons learned so far.

- *Elsie Evans*, Ambassador Programme Manager, FH Europe Foundation, UK/South Africa
- *Marc Rijken*, Patient Ambassador living with elevated Lp(a), The Netherlands
- *Chyrel Lichaa*, Patient Ambassador living with HoFH, Lebanon

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.

- *Emma Print*, Community Engagement Manager, FH Europe Foundation, UK
- *Joanna Ten-Kate*, Patient Community Engagement and Development Lead, Global Heart Hub, Ireland
- *Annie Costelloe*, Croi Heart and Stroke Charity, Ireland

Workshop 3: Tips and tricks for successful awareness days – How can we amplify our voice for lasting impact based on the experience with the World Heart Day?

- *Borjana Pervan*, Director of Strategy and Communications, World Heart Federation, Switzerland
- *Felix Krainer*, Planet Matters, Austria
- *Marie-Therese O'Donohue*, Patient Ambassador living with elevated Lp(a), Switzerland/Ireland

Workshop 4: FHEF leadership in EU projects – Address opportunities for the Network to get involved.

- *Magdalena Daccord*, Chief Executive Officer, FH Europe Foundation, Switzerland
- *Prof. Joanna Lane*, Chairperson, FH Europe Foundation, The Netherlands

17:00 – 19:30 Free time

19:30 – 23:00 Gala dinner with a Keynote by Prof. Florian Kronenberg, Austria

- Moderated by *Lena Rosa Hanauer*, Austria, and *Aedan Kaal*, The Netherlands

Sunday 10 November

7:15 – 8:15 **Morning Nordic Walk/ Fun Run to Schoenbrunn Palace**

- **Emma Print**, Community Engagement Manager, FHEF, UK
- **Marc Rijken**, Patient Ambassador living with elevated Lp(a), The Netherlands
- **Marc Amsler**, FH Europe Foundation

9:00 – 9:05 **Welcome to the second day and agenda overview**

- Moderated by **Emma Print**, Community Engagement Manager, FH Europe Foundation, UK

9:05 – 9:50 **Debrief from the breakout rooms and workshops**

- Moderated by **Elsie Evans**, Ambassador Programme Manager, FH Europe Foundation, UK/South Africa

9:50- 10:30 **Four examples of excellence from the FHEF Network**

- Moderated by **Emma Print**, Community Engagement Manager, FH Europe Foundation, UK
- FH Paediatric screening White Paper – Anhet.f, **Maria Nassif**, France
- Engaging Community for Awareness – Croi, **Annie Costello**, Ireland
- Patient organisation, screening and public engagement, **Iva Prgomet (online)**, **Prof. Ivan Pećin**, Croatia
- The Power of One Ambassador, **Teevi Poobus**, Estonia

10:30- 11.00 **Active Break**

11:00 – 11:30 **Looking back on the last year's key achievements**

- **Emma Print**, Community Engagement Manager, FHEF, UK

11.30 – 12:20 **Looking forward - FHEF's long-term strategy**

- 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.
- **Nicola Bedlington**, Sr Policy Advisor, FHEF, Austria

12:20 – 12:50 **Presentation of the 2025 work plan by the FHEF Team**

- **Magdalena Daccord**, CEO, FHEF, The Netherlands

12:50 – 13:00 **Closing remarks and the next annual meeting**

- **Magdalena Daccord**, CEO, FHEF, The Netherlands

13:00- **Lunch and goodbyes**

With grateful thanks to Local Partners for their great collaboration in organising this event.



Made possible thanks to the support from Our Industry Partners:

