

FHEF ANNUAL NETWORK MEETING 2025 14 – 16 November 2025, Zagreb, Croatia

Agenda (vs. 2025.09.30)

Hybrid event, Zagreb, Croatia, 14-16 November 2025

Friday, 14 November

Morning	Advisory boards, ancillary meetings, etc
13:30 – 15:00	FHEF Board Meeting (by invitation only)
16:00 – 18:00	FHEF Industry Roundtable meeting (by invitation only)
19:00 – 22:00	Registration and Welcome reception with a buffet dinner (All)

Saturday, 15 November

Welcome and Introductions 9:00 - 9:30

- Joanna Lane, FH Europe Foundation Chair
- Magdalena Daccord, FH Europe Foundation CEO
- Ivan Pećin, Croatian Atherosclerosis Society, Vice President, Croatian Rare **Diseases Society**
- Iva Prgomet, Croatian FH Patient Alliance President
- 9:30 10:00Keynote address by MEP Romana Jerković, Vice Chair of the SANT (Public Health) Committee in the European Parliament and Chair of the MEP Cardiovascular Health Group
- 10:00 10:45Panel Discussion: How do we build on recent advocacy successes to date, challenges and lessons learned and move forward in our four key disease areas
 - Florian Kronenberg, Lp(a) International Task Force Chair, Medical University of Innsbruck
 - Chyrel Lichaa, Young Patient Ambassador living with HoFH
 - **Aedan Kaal**, Young Patient Ambassador living with elevated Lp(a)
 - Kitti Almer, FH Europe Foundation Advocacy and Policy Manager
 - Tobias Silberzahn, Patient Ambassador living with elevated Lp(a), Biochemist and Immunologist
 - Marius Geanta, Centre for Innovation in Medicine Founder, Romania













10:45 - 11:15 Networking coffee break

11:15 – 12:15 Patient Engagement in Medicines Development – current trends with a spotlight on CEE and the Balkan Region

- Ingrid Klingman, FH Europe Foundation Trustee, European Forum for Good Clinical Practice (EFGCP) Board Chair
- Marko Korenjak, European Liver Patients Association (ELPA) President

Q&A

12:15 – 12:45 Panel discussion with network members and industry – how can we advance meaningful involvement with our community through FHEF

- Magdalena Daccord, FH Europe Foundation CEO
- Ingrid Klingman, FH Europe Foundation Trustee, European Forum for Good Clinical Practice (EFGCP) Board Chairman
- Marko Korenjak, European Liver Patients Association (ELPA) President
- Iva Prgomet, Croatian FH Patient Alliance President
- Daniel De Shryver Patient Engagement Advocacy Lead, J&J

12:45 - 13:45 Lunch

Afternoon: Parallel Workshops

13:45 – 15:15 Parallel Workshops:

- Workshop 1: FHEF projects state of play –key strategic questions to the network (led by Magdalena Daccord)
- Workshop 2: The value of health data and how can the FHEF harness this (led by Tobias Silberzahn).
- Workshop 3: Artificial Intelligence (AI) How can this help in your organisation's work (led by Madalina lamadei)
- Workshop 4: Ambassador Programme building the next phase (led by Elsie Evans)

15:15 – 15:45 Coffee break

15:45 – 17:15 Parallel Disease Specific Workshops

Introduction by **Matt Johnson**, EURORDIS, on the recently launched <u>Toolkit on mental health</u>. The workshops will focus on how to adapt/ implement/ socialise this toolkit in each disease area.

- HeFH
- Lp(a)
- HoFH
- FCS

17:15 – 19:00 Free time

19.00 – 23.00 Gala/Celebration Dinner

Sunday 16 November

9:00 – 9:30	Feedback from the Workshops
9:30 – 10:30	Spotlight on national and individual successes in the last year — what can be replicated in other countries or taken to scale, in mini ted talk format
10:30 – 11:00	Coffee break
11:00 – 12:15	FHEF Strategy and Governance – and why it matters Looking forward to 2026 – main pillars of our work plan and how you can engage
	Magdalena Daccord, FH Europe Foundation CEO
12:15 – 12:30	 Closing Magdalena Daccord, FH Europe Foundation CEO
12:30 -	Goodbye lunch
14:00 - 16.00	5 km Run4FH

Post-event webinars, January 2026 (tbc)