



# FH Europe Foundation Annual Network Meeting 2025



**14 - 16 November, Zagreb, Croatia**

## Agenda

### Friday, 14 November

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- 16:00 – 18:30** FHEF Industry Roundtable meeting (by invitation only, *8<sup>th</sup> floor, meeting room South 3*)
- 19:00 – 22:00** Registration and Welcome reception with a buffet dinner (*All, ground floor, Lounge*)

### Saturday, 15 November

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*The meeting will take place on the 8<sup>th</sup> floor*

**9:00 – 9:30** Welcome and Introductions

Moderated by **Nicola Bedlington**, Sr Policy Advisor (Austria)

- **Joanna Lane**, FH Europe Foundation (Netherlands)
- **Magdalena Daccord**, FH Europe Foundation (Switzerland)
- **Ivan Pećin**, Croatian Atherosclerosis Society (Croatia)
- **Iva Prgomet**, Croatian Dyslipidaemia Patients Association (Croatia)

**9:30 – 9:50** Keynote address by **Romana Jerković**, Member of the European Parliament (Croatia), Vice Chair of the SANT (Public Health) Committee in the European Parliament and Chair of the MEP Cardiovascular Health Group

**9:50 – 10:40** Implementation for impact – Engaging policy makers for policy change. The case of elevated Lp(a).

Moderated by **Mădălina Iamandei**, Patient Ambassador living with HeFH (Belgium)

- **MEP Romana Jerković**, Member of the European Parliament (Croatia tbc)
- **Kitti Almer**, FH Europe Foundation Advocacy and Policy Manager, former Health Attaché (Hungary)
- **Florian Kronenberg**, Chair of Lp(a) International Task Force, Medical University of Innsbruck (Austria)
- **Zanfina Ademi**, Head of Health Economics and Policy Evaluation Research (HEPER) Group, Monash University (Australia)
- **Marius Geantă**, President and Co-Founder of Centre for Innovation in Medicine (Romania)

**10:40 – 11:10** Networking break



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**11:10 – 11:40**     ***How do we build on advocacy successes to date, challenges and lessons learned and move forward in our four key disease areas. Panel discussion.***

Moderated by **Mădălina Iamandei**, Patient Ambassador living with HeFH (Belgium)

- **Chyrel Lichaa**, Patient Ambassador living with HoFH (Lebanon)
- **Aedan Kaal**, Patient Ambassador living with elevated Lp(a) (Netherlands)
- **Scott Reavis**, Patient Ambassador living with FCS (USA)

**11:40 – 12:15**     ***Patient Engagement in Medicines Development – current trends with a spotlight on CEE and the Balkan Region. Panel discussion.***

Moderated by **Nicola Bedlington**, Sr Policy Advisor (Austria)

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

**12:15 – 13:00**     ***How can we advance meaningful involvement with our community through FHEF in medicines development? Panel discussion.***

- **Vanessa Pott-Semêdo**, Head of Global Patient Engagement  
Boehringer Ingelheim (Germany)
- **Ivan Pećin**, Croatian Atherosclerosis Society, Vice President, Croatian Rare Diseases Society, (Croatia)
- **Iva Prgomet**, Croatian Dyslipidaemia Patients Association (Croatia)
- **Elsie Evans**, FHEF Ambassador Programme Manager (UK)
- **Ingrid Klingmann**, FH Europe Foundation Trustee, European Forum for Good Clinical Practice (EFGCP) Board Chairman (Belgium)
- **Marko Korenjak**, European Liver Patients Association (ELPA) President (Slovenia)

**13:00 – 14:00**     ***Lunch break (Hotel Restaurant, ground floor)***

**14:00 – 15:15**     **Parallel Workshops:**

- **Workshop 1: Empowering inherited lipids community for policy and advocacy – a step-by-step toolkit.** (led by Kittie Almer)
- **Workshop 2: The value of health data and how can FH Europe Foundation harness it.** (led by Tobias Silberzahn)
- **Workshop 3: Artificial Intelligence (AI) - How can this help in your organisation's work.** (led by Mădălina Iamandei)

**15:15 – 15:45**     **Networking break**

**15:45 – 17:00**     ***There is no health without mental health. EURORDIS Toolkit on mental health presentation followed by disease-specific workshops.***

Moderated by **Nicola Bedlington**, Sr Policy Advisor (Austria)

- **Matthew Bolz-Johnson**, EURORDIS Mental Health Lead and Healthcare Advisor (UK)

**Parallel Workshops:**

- Mental health and wellbeing and HeFH – **Gergely Jambrik** (Hungary)
- Mental health and wellbeing and high Lp(a) – **Marie-Therese O'Donohue** (Switzerland)
- Mental health and wellbeing and HoFH – **Marius Scheepers** (UK)
- Mental health and wellbeing and FCS – **Scott Reavis** (USA)

<b>17:00 – 17:15</b>	<b>Wrap up – Nicola Bedlington</b>
<b>17:15 – 19:00</b>	<b>Free time</b>
<b>19.00 – 23.00</b>	<b>Gala/Celebration Dinner</b> led by the Youth Group Ambassadors (8 <sup>th</sup> floor) Achievement Awards Inspirational Keynote by Prof. Ivan Pecin

## Sunday 16 November

*The meeting will take place on the 8<sup>th</sup> floor*

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Moderated by **Nicola Bedlington**, Sr Policy Advisor (Austria)

<b>8:45 – 9:30</b>	<b>Feedback from the Workshops (6min per group)</b>
<b>9:30 – 10:30</b>	<b>Spotlight on FHEF Network Member Organisations with Q&amp;As</b> <ul style="list-style-type: none"> <li>• <b>Croatian Dyslipidaemia Patients Association, Iva Prgomet</b> (Croatia)</li> <li>• <b>FH Australia – Jenny Della-Vedova</b> (Australia)</li> <li>• <b>FH China – Nazhen (Jenna) Chen</b> (China)</li> <li>• <b>Italian Association of Patients with Heart Failure (AISC), Salvatore Di Somma</b> (Italy)</li> </ul> <p><b>Q&amp;A</b></p>
<b>10:30 – 10:45</b>	<b>Networking break</b>
<b>10:45 – 11:35</b>	<b>FHEF Patient Council and Charter moving forward</b> <ul style="list-style-type: none"> <li>• <b>Mădălina Iamandei</b>, FH Patient Ambassador (Belgium)</li> <li>• <b>Chyrel Lichaa</b>, FH Lebanon (Lebanon)</li> <li>• <b>Lena-Rosa Hanauer</b>, FHchol (Austria)</li> </ul>
<b>11:35 – 12:20</b>	<b>Looking forward to 2026, the work plan and how you can engage</b> <ul style="list-style-type: none"> <li>• <b>Magdalena Daccord</b>, FH Europe Foundation CEO</li> </ul>
<b>12:20 – 12:30</b>	<b>Closing</b> <ul style="list-style-type: none"> <li>• <b>Magdalena Daccord</b>, FH Europe Foundation CEO</li> </ul>
<b>12:30 -13:30</b>	<b>Lunch</b> ( <i>Hotel Restaurant, ground floor</i> )
<b>14:00 – 16.00</b>	<b>Run4FH – a public event, 5km run*</b>

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The Annual Network Meeting will be followed by a series of Webinars on EAS/ESC Dyslipidaemia Guidelines