

# Annual Network Meeting

Zagreb, Croatia

**13-16 NOVEMBER 2025**

## EVENT REPORT





# Overview | From Community to Impact

The FH Europe Foundation (FHEF) Annual Network Meeting 2025 took place in **Zagreb, Croatia**, at a pivotal moment for cardiovascular health, rare diseases, and patient leadership in Europe and beyond. Far from being a routine annual gathering, this meeting marked a transition point: from building a strong, connected community to mobilising that community for measurable impact.

With the forthcoming **European Cardiovascular Health Plan**, renewed momentum around a European Rare Diseases framework, and growing global recognition that prevention is both possible and cost-effective, the timing of the meeting was deliberate. The Zagreb meeting was designed not only to reflect on progress, but to equip, align, and activate the FHEF Network for the next phase of delivery.

Over three days, the meeting convened a diverse, international, and multi-stakeholder community, reflecting the breadth and maturity of the FHEF network. All four inherited lipid disorders at the heart of FHEF's mission—heterozygous familial hypercholesterolaemia (HeFH), homozygous familial hypercholesterolaemia (HoFH), elevated lipoprotein(a) [Lp(a)], and familial chylomicronaemia syndrome (FCS)—were represented, ensuring that discussions reflected both common challenges and disease-specific realities.

## Why Zagreb mattered

Hosting the Annual Network Meeting in Croatia was both symbolic and strategic. Croatia has emerged as a **European example** of what is possible when political leadership, clinical expertise, and patient advocacy align, particularly in early detection, paediatric screening, and public awareness. By convening the Network in Zagreb, FHEF intentionally highlighted the **Central, Eastern and Balkan regions**, reinforcing the importance of equity, regional collaboration, and shared learning across Europe.

The meeting also demonstrated that patient leadership is no longer peripheral to science, policy, or health system design. Throughout the programme, people with lived experience were not invited as observers or storytellers alone, but as co-creators, moderators, panellists, and facilitators, shaping conversations on policy, medicines development, data, artificial intelligence, and mental health.

## From discussion to capability

The 2025 programme was structured around a clear shift in emphasis: **moving beyond awareness-raising toward practical capability building**.

Rather than focusing solely on “*what*” needs to change, sessions and workshops were designed to explore

### ANNUAL NETWORK MEETING 2025 AT A GLANCE

Held in Zagreb, Croatia, the Annual Network Meeting brought together **over 100 participants** (85 in person; 17 online) from **27 countries**, representing patients and caregivers, patient organisations, clinicians, researchers, policymakers, regulators and industry partners. All four inherited lipid disorders central to FHEF's mission—**HeFH, HoFH, elevated Lp(a) and FCS**—were represented. Post-event feedback indicated very high satisfaction (average **9.4/10**), with participants highlighting community, capability-building and mental health as defining themes.

how change happens in practice—how policy windows are used, how evidence is translated into political asks, how patients engage meaningfully in medicines development, and how communities support mental well-being alongside clinical care.

This approach was reinforced through interactive workshops, role-play exercises, and disease-specific breakouts, enabling participants to test tools, share strategies, and build confidence. Follow-up discussions after the meeting confirmed that many participants left not only informed, but better equipped to act within their national and regional contexts.

## A turning point for the Network

Feedback from participants consistently highlighted three defining features of the Zagreb meeting:

- A deeper sense of belonging and trust, described by many as “*family*”, but grounded in professionalism and shared purpose;
- A reframing of mental health as an essential, not optional, component of living with inherited lipid disorders;
- A clear appetite for continuity, with strong calls to translate momentum into concrete outputs, tools, and ongoing engagement throughout 2026.

Taken together, these signals point to a network that is maturing—one that expects structure, accountability, and follow-through, alongside solidarity and inspiration.

## Purpose of this report

This report is not intended to be a transcript of sessions or a chronological summary of presentations. Instead, it captures:

- the strategic intent behind the meeting,
- the capabilities and insights that emerged, and
- the directions and priorities identified by the community moving forward.



# Overview | From Community to Impact

## Participation, Reach and Community Feedback

### Who came together

In total, over 100 participants took part in the meeting, with 85 attending in person in Zagreb and 17 joining online, representing 27 countries across Europe and beyond. Participants included patient organisation leaders, people living with inherited lipid disorders, caregivers, clinicians, researchers, policymakers, regulators, and industry representatives.

The participation from Central, Eastern and Balkan regions, alongside long-standing network members from across Europe and beyond including the USA, China, Australia, and the UAE, reinforced the meeting's focus on equity, regional collaboration, and cross-border learning.

All four inherited lipid disorders central to FHEF's mission were represented. This ensured that discussions balanced shared priorities, such as prevention and access, with disease-specific realities, including rarity, diagnostic challenges, and treatment pathways.

### How participants experienced the meeting

Post-event survey results indicate a very high level of overall satisfaction, with an average score of 9.4 out of 10. However, the qualitative feedback reveals more than satisfaction alone—it points to confidence gained, identities strengthened, and motivation renewed. Participants repeatedly described the meeting as a space that combined psychological safety with strategic ambition. Many arrived feeling uncertain or overwhelmed, and left with a stronger sense of agency, belonging, and direction:

*"I arrived nervous and left proud, lighter, and more determined than ever."*

*"That shared understanding, and the warmth and strength that flowed from it, has changed something fundamental in me."*

The opportunity to connect across countries, conditions, and roles emerged as a defining feature of the experience. Feedback highlighted not only the intensity of networking, but its quality—described as energising, honest, and purposeful:

*"The connections were electric, conversations flowed non-stop, and the energy from everyone—patients, advocates, clinicians—was simply brilliant."*

*"It always feels like a family."*

Importantly, participants emphasised that this sense of community did not dilute professionalism or ambition. On the contrary, many noted that the combination of lived experience and expertise strengthened discussions on policy, research, and system change, making them more grounded and more actionable.

### Beyond satisfaction: signals of a maturing Network

Survey responses and two group feedback sessions suggest that the Zagreb meeting marked a shift in expectations within the community. Participants expressed strong appreciation for the content and format, but also articulated a clear desire for continuity, follow-through, and tangible outcomes.

Rather than viewing the Annual Network Meeting as a standalone event, many now see it as:

- a checkpoint in an ongoing strategy,
- a place to build skills and confidence, and
- a launchpad for work that continues throughout the year.

This evolution—from gratitude to expectation—is a key indicator of a maturing network, ready to move from inspiration to implementation.





# Opening Remarks | From Influence to Delivery

The opening of the Annual Network Meeting 2025 established a clear message: the FHEF community has moved **from influence to responsibility**. The tone was confident, forward-looking, and focused on delivery—reflecting a **network that is no longer emerging, but ready to lead**.

## A strategic community with shared responsibility

Opening the meeting, **Prof. Joanna Lane** (*picture below*), Chair of FHEF, emphasised the evolution of the community **from individual patient voices into a connected, strategic network** that actively shapes science, policy, and research. This shift was evidenced by the Foundation's leadership role in major EU-funded initiatives, including **PERFECTO, FH EARLY, and PerMed FH**, demonstrating a community that is increasingly coordinated, credible, and impactful.



Partnerships were framed as a core enabler of this progress—but only when grounded in **ethics, transparency, and shared values**. Compliance with EFPIA and MedTech codes was described as a minimum standard rather than an ambition, with a clear expectation that collaboration must go further to maximise public benefit.

**Patient leadership** was positioned as central to the meeting's purpose, with a strong emphasis on **inclusive leadership, cross-disease learning, and the meaningful involvement of younger and underrepresented voices**. The message was unequivocal: **patient leadership is not symbolic—it is strategic infrastructure for better health outcomes**.

## From advocacy to ownership

Building on this, **Magdalena Daccord** (*picture below*), Chief Executive Officer of FHEF, reflected on the organisation's ten-year journey—**from a small group of advocates entering the European Parliament with a simple message, to an international foundation shaping public health agendas across Europe and beyond**.

That message remains unchanged: **cardiovascular disease is preventable—if prevention is chosen**. What has changed is the position of the community itself:



***"We are no longer asking for a seat at the table. We are building the tables and we invite others to join us."***

**Inherited lipid disorders** were framed as both a global challenge and a public health opportunity, affecting an estimated **1.4 billion people worldwide, including 150 million in Europe**. Positioned at the heart of cardiovascular disease, they represent one of the most powerful yet underused levers for **prevention, early intervention, and political leadership**.

Croatia was highlighted as a proof point—demonstrating what is possible when patient organisations, clinicians, and policymakers work in alignment. Its progress in early detection, structured screening, and access to care was summarised in a principle that resonated throughout the meeting: **failure is not an option**.

## Croatia as a living example of partnership in action

Welcoming participants on behalf of the **Croatian co-hosts, Prof. Ivan Pećin, President of the Croatian Atherosclerosis Society and Iva Prgomet, President of the Croatian Dyslipidaemia Patient Association** and a Young Patient Ambassador reinforced the meeting's central theme: **real change happens when people unite around a common purpose.**

They highlighted the significance of bringing together patients, clinicians, researchers, policymakers, and partners from across Europe and beyond, describing the meeting as a reflection of what collaboration can achieve in practice. Prof. Pećin used the Licitar hearts, a symbol of Zagreb, placed on each table as a metaphor for the FHEF journey—something **built with care, creativity, and commitment**—and encouraged participants to actively share knowledge and raise awareness, noting that inherited lipid disorders require attention, resources, and collective action.

Croatia's progress in FH awareness was presented not as an endpoint, but as a **shared achievement driven by partnership.** National preschool screening initiatives, public awareness campaigns, and efforts to strengthen health

literacy and early detection were all cited as outcomes of sustained collaboration, with science guiding practice and patients shaping priorities.

Speaking from lived experience, Iva Prgomet, underlined that **awareness and early detection are not abstract goals, but life-saving interventions.** Her personal story illustrated the value of timely diagnosis, while also reminding the audience that many families are still diagnosed too late. Living with FH, she emphasised, is about more than medication—**it requires understanding, support, and empowerment.**

Initiatives such as **Run4FH** were highlighted as practical expressions of this *Hunt for silent killer* and approach, reinforcing that FH is not something that limits people, but something that mobilises them to move forward. The launch of Croatia's national FH patient organisation's website further demonstrated a commitment to making knowledge accessible and ensuring that no one is left behind.

The Croatian hosts concluded by reaffirming the importance of **patient-professional partnerships and practical solutions** that genuinely improve lives—capturing the spirit of the meeting in a shared conviction: meaningful progress may be difficult alone, but together it becomes possible.

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Iva Prgomet and Prof. Ivan Pećin



# Keynote

## Romana Jerkovic, MEP

In her keynote address, Romana Jerković, Member of the European Parliament (Croatia), framed the Annual Network Meeting 2025 as a **decisive moment for FHEF**—one in which cardiovascular health must move from aspiration to action. A long-standing advocate for the community, she has consistently supported its work at European level through her roles as Chair of the MEP Cardiovascular Health Group and Co-Chair of the SANT (Public Health) Committee in the European Parliament.

Welcoming participants to Zagreb, she paid tribute to the patient leaders, caregivers, ambassadors, clinicians and partners gathered, recognising the strength of a community that has transformed inherited lipid disorders from overlooked conditions into a shared European concern. Recalling a recent gathering in the [European Parliament](#), she reaffirmed a central message underpinning the meeting:

***“Prevention is not a cost – it is our smartest investment.”***

She stressed that this commitment cannot remain confined to Brussels. Real change, she argued, takes root in communities—where patients, healthcare professionals, policymakers and citizens work together to translate policy into lived reality.

### Giving science a heart and policy a human face

Jerković praised the FHEF for its evolution from a simple idea into an international movement grounded in **courage, shared knowledge and purpose**. What distinguishes the Foundation, she noted, is its ability to humanise complex systems: “It gives science a heart and policy a human face.”

Through its Ambassador programme, patient involvement and regional engagement, inherited lipid disorders are no longer abstract statistics but visible human stories—stories that can be understood, addressed and changed. The meeting’s priorities of inclusion, innovation and collaboration beyond borders, she observed, reflect precisely what the future of European health policy demands.

### Cardiovascular health and Europe's future

Placing cardiovascular disease within Europe’s broader political and economic context, Jerković challenged narrow interpretations of competitiveness focused solely on industry, defence or technology. Europe, she argued, cannot be strong without healthy citizens. With cardiovascular disease remaining the continent’s leading cause of death, prevention must be recognised as a pillar of economic resilience, social fairness and long-term sustainability. Drawing on her leadership of the Cardiovascular Health Group in the

European Parliament, she described growing cross-party momentum behind a new Cardiovascular Health Plan for Europe. The initiative aims to strengthen early detection, improve equitable access to treatment, reinforce tobacco and alcohol regulation, advance nutrition policies, and make better use of EU health data for prevention and research. She stressed that cardiovascular policy must learn from cancer strategies and connect meaningfully with the rare disease community.



### Croatia as a model ready to scale

Speaking as both a European policymaker and a Croatian representative, Jerković expressed pride that the meeting spotlighted Central, Eastern and Balkan regions, highlighting Croatia as a strong example of effective, multisectoral prevention. She pointed to **Croatia's national FH preschool screening programme**, introduced in 2023, as a pioneering public health decision enabling reverse cascade screening of families.

Combined with national prevention policies, public awareness campaigns, salt-reduction strategies and community initiatives, Croatia is demonstrating how prevention can be made visible, measurable and effective. With approximately 65% of Croatian adults living with elevated LDL cholesterol, she described these approaches as both necessary and scalable—**“ready to share, ready to copy-paste.”**

### From words to action

Turning to innovation, she acknowledged the potential of health data and artificial intelligence (AI), while underlining the need for ethical, inclusive and human-centred governance. While AI can analyse vast datasets, it cannot replace empathy.

Returning to the human dimension, she reminded participants that behind every statistic is a person, a family and a future. Empowerment begins when people understand their condition and realise they are not alone—an approach she credited the FHEF with advancing through sustained patient partnership. As she closed, Jerković described this moment as a turning point for Europe:

***“Prevention saves lives, data drives progress, inclusion fuels innovation, and community sustains change.”***

She reaffirmed her commitment, as Rapporteur for the Cardiovascular Health Report, to ensuring that Europe delivers on its promises. Her final message was uncompromising:

***“Every life lost early to preventable heart disease is a policy failure.”***

# Implementation for Impact: Engaging Policymakers for Policy Change. The Case of Elevated Lp(a) Prevention

This session marked a deliberate shift **from awareness to implementation-focused advocacy**, using elevated Lp(a) as a practical case study to demonstrate how evidence, economics and lived experience can be translated into policy change. The session opened by setting the institutional context for EU health policymaking, clarifying how proposals move between the European Commission, Parliament and Council, and why timing, clarity of ask and audience selection are critical to successful advocacy. The aim was explicit: to demystify EU institutions, showcase real-world examples, and strengthen participants' confidence to engage policymakers at both European and national levels.

## Turning EU momentum into national action

Participants were reminded that while **health remains primarily a national competence**, the EU plays a decisive role through coordination, strategy-setting and regulation. Forthcoming EU initiatives, including the **Cardiovascular Health Plan**, were highlighted as key political opportunities. [2024 Council Conclusions on Cardiovascular Health](#), although non-binding, were presented as powerful tools for generating political momentum—creating commitments that civil society can use to hold governments to account. The core advocacy message was clear and pragmatic: effective engagement requires precision, solution-oriented asks, and strategic use of EU-level commitments to reinforce national advocacy efforts.

## Bridging the implementation gap

From a scientific perspective, the session highlighted the persistent gap between evidence and practice in Lp(a). Despite strong scientific consensus and existing guidelines, implementation remains delayed—often by more than a decade. Outcomes from the **Global Lp(a) Summit in Brussels** were used to illustrate how researchers, clinicians, patients and policymakers can align around clear policy asks, including systematic Lp(a) testing and once-in-a-lifetime screening. Importantly, Lp(a) was positioned not as a standalone issue, but as part of a broader cardiovascular risk profile. Participants were reminded that precision medicine means addressing the whole risk landscape, rather than focusing on a single biomarker in isolation.

From left to right: Mădălina Iamandei (Belgium/Romania), Moderator and Patient Ambassador; Dr. Marius Geantă (Romania), President of the Centre for Innovation in Medicine; Prof. Florian Kronenberg (Austria), Chair of the Int. Lp(a) Task Force; Kitti Almer, Policy/Advocacy Manager at FHEF and former Health Attaché (Hungary); on screen: P. Prof. Zanfina Ademi, Monash University (Australia) **10**

## The economic case for action

Compelling health economic evidence demonstrated that Lp(a) testing is **not only cost-effective, but cost-saving**. Modelling showed that without Lp(a) measurement, around one in five individuals are misclassified into lower-risk categories, delaying preventive interventions. Early identification enables timely management of modifiable risk factors such as LDL-C and blood pressure, leading to improved outcomes and reduced long-term costs at both national and population levels. The conclusion was unequivocal: **investing in Lp(a) testing saves both lives and public resources**.

## Coalition-building as a driver of change

Practical examples of implementation underscored the importance of trust-based, multi-stakeholder coalitions. Drawing on experience from Romania, participants explored how long-term advocacy—supported by clinicians, patient organisations, policymakers and researchers—can reshape health systems, even when progress takes years to materialise. Integrated, people-centred approaches, including community-based **“living labs”**, demonstrated how cardiovascular prevention can be embedded alongside broader public health priorities.

## Key takeaway for the Network

The session closed with a reminder that elevated Lp(a) is one example of a much wider challenge. The advocacy principles explored—clarity of ask, alignment of evidence and economics, coalition-building, and sustained engagement—apply equally across other inherited lipid disorders. With one in five people (est. 1.4 billion) affected by elevated Lp(a), participants left with a clear understanding that this is not a niche issue, but a **mainstream prevention opportunity**—and one that patient advocates are well placed to drive forward.



# How do we build on Advocacy Successes to date, Challenges and Lessons Learned and Move Forward in our Four Key Disease Areas

This session demonstrated how prepared, patient-led advocacy is already delivering tangible impact across FHEF's four key disease areas. Drawing on lived experience from different national and political contexts, ambassadors illustrated that while challenges vary, the core drivers of successful advocacy are strikingly consistent.

## From participation to leadership

Across all examples, a clear shift emerged: **patients are no longer passive participants but co-leaders of advocacy efforts**. Structured preparation, clarity of roles, and early involvement were repeatedly highlighted as decisive factors in success. Advocacy initiatives gained traction when patients were embedded from the outset—helping to shape agendas, messages and engagement strategies rather than reacting to decisions already taken.



As **Aedan Kaal (The Netherlands), Patient Ambassador living with elevated Lp(a)**, illustrated, effective advocacy depends on being **concise, timely and politically aware**. Recent youth consultation by the European Commission and the Lp(a) Global Summit succeeded because patient voices were strategically integrated

and aligned with political momentum. The ability to clearly articulate key messages—sometimes in under a minute—was identified as critical to converting attention into action.

## Lived experience as a strategic asset

A second unifying theme was the power of lived experience when combined with **preparation and policy literacy**. Advocacy was most effective when personal stories were not presented in isolation, but supported by data, evidence and a clear understanding of decision-making processes.

Reflecting on the Ambassador Programme, **Mădălina Iamandei (Belgium/Romania), Patient Ambassador living with HeFH**, highlighted how the combination of **human experience and technical knowledge creates credibility** across audiences—from policymakers and clinicians to industry stakeholders. When patients speak with confidence and clarity, attention follows.



## Visibility, courage and relationship-building

The session also underscored the importance of visibility and relationship-building. Advocacy impact was not confined to formal meetings, but extended to informal interactions, repeated presence and the willingness to be seen and heard.

Drawing on his experience **living with FCS, Scott Reavis (USA)** demonstrated how **storytelling, humour and energy can open doors** that technical arguments alone cannot. His message was clear: advocacy does not require perfection, but presence—and every individual has the potential to spark awareness.



## Precision, urgency and moral authority

Finally, the session highlighted how focused, time-bound advocacy can succeed even in highly constrained environments. Speaking from the context of Lebanon, **Chyrel Lichaa (Lebanon), Patient Ambassador living with HoFH**, described restoring access to life-saving apheresis during political transition through a **combination of precise documentation, compelling data and lived experience**. Limited time with decision-makers was used strategically, while the presence of patients and families added moral authority that statistics alone could not provide.



## Key takeaway for the Network

Taken together, these experiences reinforced a shared conclusion: successful advocacy is **intentional, prepared and deeply human**. When data opens the door, lived experience creates the connection that enables change. These principles—clarity of message, early patient leadership, strategic storytelling and coalition-building—are transferable across diseases, countries and political systems, offering a blueprint for future advocacy across the FHEF Network.

# Patient Engagement in Medicines Development Education as the Enabler of Partnership

This session reinforced a central principle for medicines development: meaningful patient involvement is **only possible when patients are educated, prepared and engaged early**. Moving beyond symbolic participation, the discussion positioned patients as strategic partners whose expertise improves relevance, feasibility and outcomes across the development lifecycle.

**Ingrid Klingmann, FHEF Trustee and Chair of the Board at the European Forum for Good Clinical Practice (EFGCP) Board**, framed patient involvement as **both a scientific and ethical imperative**. Drawing on lived experience and



decades of work in clinical research, she described the evolution from “patient-centricity” towards genuine involvement—where patients contribute to concept development and early decision-making, rather than being consulted once key choices are already fixed.

*“Impact happens at the beginning... patients need to be involved early, where decisions are made.”*

A shared enabler across all examples was structured patient education. Early initiatives revealed that while patients were motivated to contribute, lack of system knowledge limited their influence. This gap led to the development of [EUPATI](#) (European Patients' Academy on Therapeutic Innovation), which has since trained thousands of patient experts globally and created a shared knowledge base for patients, regulators, academia and industry.

Building on this, **Marko Korenjak, President of the European Liver Patients Association (ELPA)**, illustrated how **training transforms participation into partnership**. He highlighted how educated patient advocates can influence both research design and regulatory decisions—improving feasibility without compromising science.



*“We are not aiming to be the subjects of medicine—we are aiming to be partners.”*

The discussion also highlighted **regional differences**: while Western Europe has more structured patient involvement, Central and Eastern Europe bring strong motivation and engagement. Combining these strengths—through

cross-disease collaboration and networks such as FHEF—was identified as a clear opportunity. The key message was unequivocal: **unprepared participation risks undermining credibility**, while education and professionalisation enable patients to co-design better, more efficient and more equitable medicines development.

## Why Pharma Needs Patients at the Centre of Drug Development

This session addressed the practical and strategic reasons why meaningful patient involvement is essential to successful medicines development. Speaking from an industry perspective, **Vanessa Pott-Semêdo, Head of Global Patient Engagement at Boehringer Ingelheim**, argued that involving patients is both logical and long overdue.

The core premise was simple: in most sectors, organisations routinely ask their customers what they need. Medicines development, she argued, should be no different. **Patients and families bring insights that no other stakeholder can provide**, particularly on how conditions affect daily life, priorities, and trade-offs—long before any molecule is developed.

From early research onwards, patient organisations increasingly contribute to shaping research priorities by highlighting unmet needs beyond biology alone. These insights help ensure that development programmes **focus on outcomes that matter most to people** living with a condition.

**Patient involvement is equally critical in clinical trials**. Feedback from participants frequently identifies when protocols are overly burdensome or impractical. In response, trial designs have been adapted—simplifying procedures, adjusting visit schedules, and providing practical support such as transport or childcare. Patients also help define meaningful endpoints, including patient-reported outcomes such as fatigue, which may otherwise be underestimated but have a major impact on quality of life.

Beyond research and trials, patient voices play a vital role in **improving diagnosis, awareness and access to treatment**. Many barriers persist due to limited understanding among healthcare professionals and decision-makers. In this context, patient organisations and industry share a common interest: ensuring that innovation translates into real-world benefit.

# Advancing Meaningful Involvement through FHEF | From Education to Co-Creation

This session focused on how the FHEF can systematically advance meaningful patient involvement in medicines development, moving beyond consultation **towards genuine partnership and co-creation**. Contributions from patient leaders, clinicians and programme leads reinforced a shared conviction: involvement delivers impact only when patients are educated, empowered and engaged early.

Across perspectives from **Ivan Pećin** (in picture below), **Iva Prgomet**, **Ingrid Klingmann**, **Marko Korenjak**, and **Elsie Evans** (FHEF Ambassador Programme Manager), the discussion consistently highlighted **structured education**—notably programmes such as EUPATI—as the foundation for credible engagement. Training equips patient advocates with the **knowledge, confidence and legitimacy** required to engage effectively with scientists, regulators, clinicians and industry as informed equals.

While the learning journey was acknowledged as demanding—particularly in relation to scientific, regulatory and statistical concepts—it was described as ultimately empowering. Education enables patients to contribute strategically rather than symbolically, strengthening both the quality and credibility of their input.

Participants emphasised that **patient involvement must begin early**, ideally at the ideation and design stages of medicines development, rather than being limited to late-stage protocol review. Practical mechanisms discussed included community advisory boards, expansion of the Ambassador Programme, and modular, accessible education pathways that allow participation across different levels of experience and capacity.

The session also underlined the **importance of communication skills, personalisation** (including gender differences), and the complementary roles of healthcare professionals, patient organisations and advocates in **ensuring that medicines are not only developed, but are usable, acceptable and effective** in real life.

The shared vision was clear better medicines require better partnership. As summarised by Elsie Evans:

*“Real breakthroughs in medicines development and patient engagement will only come when patients are valued as co-creators—where lived experience helps shape decisions about what treatment really means for individuals.”*



# Workshops From Knowledge to Capability

The three parallel workshops were **designed to support and operationalise the plenary sessions**, translating strategic discussions on policy and advocacy, patient engagement in clinical trials, and understanding health data and the use of artificial intelligence in health into practical learning. They were intentionally designed as interactive and energising elements of the Annual Network Meeting, moving participants from discussion to hands-on skill building.

Across advocacy, health data and artificial intelligence, the workshops focused on equipping the FHEF community with **practical tools, confidence and a shared language** to operate more effectively in complex policy, research and digital environments. By combining **structured frameworks, real-world examples and participatory exercises**, the sessions enabled participants to test ideas, ask difficult questions and build capabilities that can be applied directly within their organisations and national contexts.



## Empowering inherited lipid disorders community for policy and advocacy

### *Advocacy as a learnable skill*

The advocacy workshop, led by **Kitti Almer**, focused on strengthening participants' ability to **engage policymakers strategically and effectively**. A key early insight was the reframing of policymakers not as distant or adversarial figures, but as time-pressured individuals who rely on external expertise, particularly from patients and clinicians.

Participants explored how **timing, political context and institutional roles shape receptiveness**, and learned

not to personalise rejection, which is often driven by agendas rather than disinterest. A practical **five-step advocacy framework—problem, solution, evidence, story and ask**—provided a clear structure for engagement. Through role-play exercises, participants practised tailoring messages to different audiences, reinforcing that preparation, clarity and empathy are decisive for impact.

## The value of health data and how can FHEF harness it

### *Health data as a shared asset*

The workshop on health data, led by **Tobias Silberzahn**, broadened understanding of what constitutes health data and why it matters—not only for research, but **for empowerment, prevention and community building**. Participants explored the value of behavioural, experiential and patient-reported data alongside clinical and genomic information, particularly in the context of rare and inherited conditions.

A central message was that **data only creates value when it is human-centred, trusted and accessible**. Tokenistic data collection, complex surveys and lack of feedback undermine engagement, whereas co-designed registries and transparent communication strengthen relevance and participation. Patient organisations were encouraged to play an active role in **shaping data strategies**, ensuring that data serves both scientific and community needs

## Artificial intelligence (AI): How can this help in your organisation's work

### *Artificial intelligence excitement, caution and responsibility*

The AI workshop, moderated by **Mădălina Iamandei**, generated particularly strong engagement and debate, reflecting both **curiosity and concern**. Participants explored how AI is already influencing healthcare through diagnostics, risk prediction, data analysis and patient-facing tools, with **potential benefits for earlier diagnosis, efficiency and access**.

At the same time, the discussion surfaced significant risks. Participants highlighted **issues of bias, accuracy, transparency and data governance**, as well as discomfort around sharing personal health information with systems whose decision-making processes are opaque. There was

strong consensus that AI cannot replace human judgement or empathy, and that uncritical use risks harming trust and widening inequalities.

The session underscored the **need for responsible, patient-informed deployment of AI in healthcare**. Participants stressed that patients, caregivers and clinicians must be involved early in design and evaluation, with clear communication about limitations and safeguards. While EU-level regulation is evolving, the workshop reinforced that patient organisations have a critical role in shaping how AI is used—ensuring it supports, rather than undermines, care.

## Key skills developed through the workshops

Across the three workshops, participants strengthened a shared **set of practical and transferable skills**. These included the **ability to frame clear, evidence-based policy asks** and **engage policymakers with confidence**; to **understand, interpret and communicate health data** in ways that are meaningful and trustworthy for patients and decision-makers; and to **critically assess the opportunities and risks of digital tools**, including artificial intelligence, in healthcare settings. Participants also developed greater confidence in tailoring messages to different audiences, co-designing solutions with stakeholders, and navigating complex ethical, regulatory and political environments. Collectively, these skills reinforce the network's capacity to move from knowledge to action and to engage as informed, credible partners across policy, research and innovation.

# There Is No Health Without Mental Health: A Turning Point for the Network

This session emerged as one of the most powerful and widely cited highlights of the Annual Network Meeting 2025. Led by **Matthew Bolz-Johnson** (in picture below), **Mental Health Lead and Healthcare Advisor at EURORDIS**, it fundamentally reframed how the FHEF community understands health, advocacy and impact.



Rather than treating mental health as a secondary or individual concern, the session positioned it as foundational to living well with inherited lipid disorders. Drawing on the World Health Organization (WHO) definition, **mental health was described as a dynamic state of well-being**—shaped not only by biology, but by relationships, community, uncertainty, stigma and lived experience. Crucially, it was framed as integral to individual functioning, community resilience and health system effectiveness.

## Making the invisible visible

Participants explored the psychosocial realities that are often overlooked in clinical pathways and advocacy discussions, including:

- the **diagnostic odyssey**, where delayed or poorly communicated diagnoses can leave lasting emotional impact;
- **ongoing uncertainty**, both long-term (future health, life planning) and short-term (appointments, results, system failures);
- **low awareness and stigma**, particularly for invisible conditions, leading to isolation and the burden of constant self-explanation;
- **biomedically focused care** that neglects mental health and quality of life, despite their influence on adherence and outcomes;
- the **impact on families and caregivers**, whose well-being directly affects those they support.

Polling data and European-level surveys reinforced the scale of the issue, revealing **high levels of anxiety, stress, depression, social isolation and financial strain**—while mental health remains rarely addressed in routine care.

The plenary session was followed by **four disorder-specific breakout workshops, moderated by designated Patient Ambassadors**. These sessions were intentionally not recorded, in recognition of the emotional depth of the discussions and the importance of creating a psychologically safe space for participants to share openly. Building on the [EURORDIS Reaching Beyond Rare Mental Health Toolkit Blueprint](#), discussions focused on shared psychosocial needs across disease areas, including resilience-building, caring connections, practical coping tools and managing daily challenges. Participants consistently described the breakout discussions as exceptionally powerful and affirming, reinforcing both the scale of unmet need and the value of peer support, validation and shared understanding.

## From awareness to action

Alongside risk factors, the session highlighted protective elements that support mental well-being, including **coordinated care, respectful communication, access to clear information, strong peer connections, and opportunities for self-efficacy and advocacy**.

A key outcome was the introduction of a **five-pillar mental health toolkit**, offering a practical framework covering self-awareness, resilience, access to information, peer support and management of common challenges such as fatigue, sleep and visibility. Participants were invited to co-create and adapt this toolkit for the FHEF community. The session marked a clear shift in perspective: **mental health is no longer peripheral to familial lipid disorders advocacy—it is central to it**.

## Key takeaways for the Network

The session made clear that mental health and quality of life (QoL) must be recognised as core components of inherited lipid disorders advocacy, rather than optional or secondary considerations. The psychosocial burden associated with inherited lipid disorders is universal across disease areas and needs to be addressed alongside clinical care, not separately from it. Participants also highlighted the **importance of generating and using robust data on mental well-being** to influence policymakers, payers and HTA processes, ensuring that quality of life is reflected in decision-making.



# Highlights from the Gala Dinner and Awards Ceremony

The Gala Dinner provided an evening of celebration, creativity, youth, reflection and appreciation, offering a fitting close to the formal programme of the Annual Network Meeting.

The evening opened with a **warm, moving and creative theatrical performance, prepared and performed by the International Young Ambassadors**. Through storytelling, humour and emotion, the piece delivered a powerful message about lived experience, resilience and hope. This collaborative initiative led by Lena-Rosa Hanauer (Austria) showcased a remarkable community of young people who are thoughtful, committed and courageous, and the performance was met with enthusiastic and heartfelt applause from the audience.

The programme then turned to moments of recognition and gratitude, celebrating outstanding contributions within the FHEF community. **Elsie Evans** (UK, South Africa) was recognised for her exceptional leadership of the Ambassador Programme and her tireless work in nurturing, strengthening and expanding the community. **Patsy Petrie**, FHEF Patient Ambassador (Scotland), was also honoured for her impactful and sustained efforts to raise awareness of inherited lipid disorders through social media, helping to reach and engage audiences far beyond traditional health spaces.

The official program concluded with a special moment of appreciation for **Prof. Ivan Pećin**, following his keynote presentation highlighting Croatia's innovative awareness campaigns, public runs and initiatives such as the "hunt for the silent killer", which have significantly increased public understanding of cholesterol and other cardiovascular risk factors. In recognition of his long-standing commitment to education, prevention and awareness-raising in the fight against cardiovascular disease, Professor Pećin was presented with an award honouring his contribution to public health and patient advocacy.

The evening, as per the tradition ended up with celebration on the dance floor. Together, these moments captured the spirit of the FHEF community—one defined by **creativity, partnership, gratitude and shared purpose**—and provided a memorable and uplifting conclusion to the Annual Network Meeting 2025.



Patient Ambassador Patsy Petrie recognised with the social media award for her outstanding efforts in raising awareness



A moment of recognition for Elsie Evans for her leadership in the Ambassador Programme and her contributions to strengthening and expanding the FHEF community.



Prof. Ivan Pećin, co-host and President of the Croatian Atherosclerosis Society, presented with an award in recognition of his significant contributions to public health, education, prevention, and awareness-raising.  
*"Failure is not an option"*



The performance concludes with a heartwarming moment as India Rijken, Marc Amsler, Jula Tobiasj, Maria Nassiff, and Lena-Rosa Hanauer engage participants of all ages, highlighting the inclusive and collaborative spirit of the Annual Network Meeting 2025.



Magdalena Daccord stands on stage with Elizete Poobus, the youngest Ambassador, symbolising why we do advocacy and highlighting a commitment to the future.



FHEF Young Ambassadors Lena-Rosa Hanauer, Marc Amsler, Jula Tobiasj and Chyrel Lichaa take centre stage, showcasing their leadership and commitment to driving impactful change with a bit of humour.



Recognition at the final gathering, these memories reflect the diverse and collaborative spirit of the gathering, showcasing participants from various



Larissa Maier, Iva Prgmot, and Leila Salihbasic



No matter your entry point to our community, this lively atmosphere reflects the camaraderie and celebratory spirit of the gathering, as participants connect and unwind after the formal sessions.

# From Reflection to Governance and the Way Forward

Day 2 of the Annual Network Meeting 2025 focused on **consolidation, reflection and future-proofing the patient voice** within the FHEF. Building on the strategic discussions and skills developed on Day 1, the programme shifted towards **governance, leadership and collective responsibility**, with a strong emphasis on embedding patient perspectives sustainably and credibly across all FHEF activities.

The morning sessions provided space for feedback and reflection on insights gained throughout the workshops, highlighting how advocacy, mental health, medicines development and innovation intersect in real life. Participants were encouraged to consider how these learnings translate into long-term structures that ensure continuity, accountability and impact beyond individual projects or events.

## Spotlight on the FHEF Network | Members in Action

Day 2 also placed a strong spotlight on the **strength, diversity and growing global reach of the FHEF Network**, highlighting both long-standing partners and new members whose work exemplifies patient leadership in action. This segment reinforced that the network is not only expanding geographically, but also **deepening in impact, collaboration and ambition**.

The spotlight included recognition of new Network members from China and Australia, reflecting the increasingly global nature of FHEF collaborations and impact, alongside the achievements of the Croatian and Italian patient organisations, whose work illustrates how sustained collaboration can drive systemic change. Together, these spotlights reinforced a central message of Day 2: **the strength of FHEF lies in its members**—their leadership, lived experience, collaboration and shared commitment to improving lives across borders.

From Croatia, **Croatian Dyslipidaemia Patients Association**, represented by **Iva Prgomet**, shared a personal and national perspective on FH. Drawing on her own diagnosis following her mother's late detection, she highlighted how FH often remains invisible despite healthy lifestyles. She emphasised the life-saving importance of early screening, trusted partnerships between patients and physicians, and Croatia's progress in paediatric screening and public awareness. Her message underscored collaboration as a powerful driver of change and reaffirmed a strong commitment to building a connected community in Croatia and beyond.



From Italy, **Italian Association of Patients with Heart Failure (AISC)**, represented by **Salvatore Di Somma**, highlighted the impact of more than a decade of structured collaboration between patients, clinicians and policymakers. He described a shift from hospital-centred care towards community-based prevention, including large-scale screening initiatives in communities and pharmacies, and a growing focus on dyslipidaemia and elevated Lp(a). His key message was that patient-generated data and active involvement in research and policy are essential to influencing decision-makers and transforming cardiovascular prevention.



New members also shared powerful perspectives from beyond Europe. Representing **FH China Patient Network**, **Nazhen (Jenna) Chen** described the severe challenges faced by people living with FH in China, particularly children and those with homozygous FH (HoFH), where late diagnosis and limited access to innovative therapies create life-threatening gaps in care. She outlined how FH China is "building a bridge of hope" through emergency patient support, long-term research investment, policy advocacy and access to clinical trials, calling for global solidarity and shared responsibility.



From Australia, **FH Australia**, **Jenny Della-Vedova** shared the journey of founding a national FH patient organisation in the absence of population screening. Through the FH & Kids study and strong cross-sector collaboration, she demonstrated how early diagnosis and treatment can enable children with FH to live a normal life expectancy. Her message focused on the power of collaboration—between patients, clinicians, charities and national heart organisations—to move from isolation to collective impact and ensure no family faces FH alone.



## Strengthening the patient voice | The FHEF Patient Council

A central focus of Day 2 was the formal presentation of the **FHEF Patient Council**, led by **Mădălina Iamandei, Chyrel Lichaa and Lena-Rosa Hanauer**. The Patient Council is a strategic body within FHEF, bringing together Patient Ambassadors from across Europe and beyond to ensure that **patient perspectives are systematically embedded across all workstreams**. The Council is designed to play a formal role in FHEF governance, contributing to decision-making, shaping messaging and educational materials, and providing structured, collective input from the patient community. Through collaboration, peer learning and leadership development, it strengthens the credibility, consistency and visibility of the patient voice. While the idea of a Patient Council had existed for several years, it became feasible to implement only recently, once both the Foundation and the community had the capacity and maturity to support it effectively.

### *The Patient Ambassador Charter | A shared framework for the future*

Closely linked to the Patient Council, Day 2 also introduced the **Patient Ambassador Charter as a foundational document guiding patient advocacy within FHEF**. The Charter formalises shared ethical principles, values, rights and responsibilities, providing a practical framework for how Patient Ambassadors engage, represent the community and contribute meaningfully to FHEF's work. **Co-created by patients**, the Charter reflects collective values of integrity, respect, equity, collaboration and empowerment. It promotes consistency, transparency and accountability, while supporting Ambassadors to work confidently and professionally with clinicians, policymakers, researchers and partners. Importantly, it also reinforces the **long-term sustainability of patient involvement** by linking advocacy to capacity building and leadership development through the Ambassador Programme.

### *Moving forward together*

The session concluded with a clear roadmap for next steps. An open consultation period will invite community members to submit written feedback and proposed amendments to the Charter. The Patient Council will review this input and develop a revised version, which will be shared again for further consultation. The aim is to finalise the Charter by the end of the year or early 2026, enabling FHEF and its Patient Council to move forward with a collectively endorsed framework guiding patient representation, leadership and advocacy.

Day 2 therefore marked a significant transition—from discussion and inspiration to structure, governance and shared ownership—laying the foundations for a stronger, and more resilient patient voice within FHEF.

## Looking Ahead to 2026 | Priorities, Implementation and How to Engage

Closing the meeting, **Magdalena Daccord, Chief Executive Officer of FHEF**, reflected on **2025 as a landmark year for policy and advocacy**. Years of coordinated, patient-led engagement have culminated in the **European Commission's Cardiovascular Health Plan**, scheduled for release on 16 December and shaped by extensive input from patients, clinicians and civil society. FHEF is preparing expert and patient-led analysis to support dissemination, interpretation and national-level implementation of the Plan. At global level, the adoption of a **United Nations Resolution on Rare Diseases**, actively supported by FHEF, marked another significant milestone. While this represents an important political commitment, the focus now shifts to sustained advocacy to ensure the Resolution translates into concrete action. Throughout 2025, awareness campaigns, international advocacy, contributions to clinical guidelines and the continued expansion of the Ambassador Programme have further strengthened global patient leadership and visibility.

### *From momentum to measurable impact*

Looking ahead, 2026 will be defined by **implementation, scale and impact**. Key priorities include structured follow-up on the EU Cardiovascular Health Plan, intensified national and international policy engagement, expert and patient roundtables, and the expansion of paediatric screening initiatives. New collaborative formats, including *Living Labs*, will be explored to support real-world implementation and cross-sector learning. The year will also feature several major milestones and opportunities for engagement, including the **PERFECTO final conference under the Cypriot EU Presidency**, a strong patient presence at the **European Atherosclerosis Society Congress** in Athens, continued participation in global scientific and policy forums, and the **next Annual Network Meeting**, planned for the second weekend of November 2026 in Ireland.

### *A shared invitation to engage*

Across both 2025 and 2026, the emphasis remains on **unified advocacy, capacity building, data, mental health and meaningful patient involvement**. Members, Ambassadors and partners were invited to actively engage—by contributing expertise, participating in consultations, and events, supporting national advocacy efforts, and helping to translate policy commitments into tangible improvements in people's lives.

The message was clear: ***the foundations have been laid. The coming year is about working together to turn progress into lasting change.***

# Run\_4\_FH\_Europe

The **RUN\_4\_FH\_Europe** event, held on 16 November 2025 in Zagreb during the FHEF Annual Network Meeting, gathered delegates, clinicians, patient representatives, families, and supporters from across Europe for a shared purpose: to raise awareness of **Familial Hypercholesterolaemia** and other inherited dyslipidaemias.

Over the years, this run has grown into a meaningful tradition in Croatia symbolising the collective commitment to early diagnosis and preventive cardiovascular care. More than a run, the event served as a visible expression of FHEF's mission—to increase the awareness about endanger of inherited dyslipidaemias, and in most of the cases unrecognised elevated Lp(a), strengthen cascade screening, broaden access to modern lipid-lowering therapies, and help health systems build comprehensive programmes. Participants of all ages joined the non-competitive run, underscoring inclusivity and the belief that awareness and prevention truly begin within the community.

This year's RUN\_4\_FH\_Europe also echoed several themes highlighted during the scientific sessions of the meeting, including:

- The need to **identify FH early**, especially in children and young adults
- Ongoing efforts to **develop and support national FH registries**
- The importance of **patient engagement and health literacy**
- The value of closer **collaboration between scientific societies, clinicians, policymakers, and patient organisations**

By bringing together local residents with international delegates, the run amplified a powerful message: FH and elevated Lp(a) remain significantly underdiagnosed worldwide, and community involvement is essential if we want to improve long-term cardiovascular outcomes. The enthusiasm and strong support seen in Zagreb reflect a growing momentum for coordinated action across Europe. RUN\_4\_FH\_Europe stands as a reminder that meaningful change happens when advocacy, education, and scientific progress move forward together—**step by step, and often quite literally, side by side.**

The run was organised in collaboration with Run Croatia.







**FHEF warmly thanks all participants, speakers and facilitators** who contributed to the Annual Network Meeting 2025 and to the spirit of collaboration that defined the Zagreb gathering. A sincere thank you also goes to every participant for their time, engagement and valuable contributions, which were central to the success of the event.

We are especially grateful to our Croatian co-hosts—the **Croatian Dyslipidaemia Patients Association** and the **Croatian Atherosclerosis Society**—for their leadership, partnership and generous welcome. We extend our appreciation to the **Programme Committee led by Nicola Bedlington** (with Helga Davidson, Iva Dimitrova, Lena-Rosa Hanauer, Madalina Iamandei, Iva Prgomet, Salvatore Disomma, Ivan Pecin, Albert Wiegman, Magdalena Daccord, Elsie Evans, Špela Bovha, Magda Anthousi, Marina Leroy), whose members served entirely on a voluntary basis, as well as to the wider organising team, for their dedication, professionalism and careful planning. FHEF is deeply grateful to all those who supported the organisation of the meeting and to everyone who contributed to FHEF activities throughout the year, for their continued involvement across the Foundation's work and for advancing its mission and impact within the community.



FHEF further extends its sincere thanks to the International Atherosclerosis Society (IAS) for endorsing the Annual Network Meeting 2025, reinforcing the meeting's scientific integrity and shared commitment to advancing atherosclerosis prevention and patient-centred care.



We extend our sincere appreciation to our sponsors—**Amgen, Arrowhead, Chiesi, Eli Lilly, Menarini and Novartis**—for their support and for their commitment to ethical collaboration, which enables patient leadership, education and advocacy across the network.



Finally, we warmly thank the **City of Zagreb** and our local partners, including the **Croatian Hypertension League, the Croatian Society for Rare Diseases**, and **Run Croatia** for their collaboration and hospitality. We also recognise the contribution of **Patient Ambassadors**, including the **International Young Ambassadors** and the **volunteer moderators** of breakout sessions, whose professionalism, courage and lived experience gave the meeting its distinctive power and purpose.



*Pictures of the event  
available here:*



*Videos of the sessions  
available here:*

