Welcome to FH Europe Foundation’s February 2025 edition of Heart Beat.

FH Europe Foundation February 2025 Heart Beat Newsletter

Welcome to the February edition of the Heart Beat newsletter!

February has been an inspiring and action-packed month for FH Europe Foundation. As we mark Rare Disease Day, we continue raising awareness for HoFH and FCS, advocating for better awareness, personalised care and equitable access to treatment. Read more about the successes of the young Ambassadors in the global EURORDIS Photo Competition.

Meanwhile, preparations for Lp(a) Awareness Day 2025 are underway, with a dedicated social media campaign and a first global summit which has gained a lot of political and scientific interest and support.

Internally, we are excited to welcome two new members to our team, strengthening our ability to drive change in the area of rare diseases and outputs in the EU funded projects.

Across our Network, organisations in Czechia, Croatia, France, Ireland, Hungary and Poland are leading efforts in education, screenings, and advocacy—ensuring those affected by inherited lipid disorders receive the support they need. Meanwhile, on the global stage, the World Health Assembly's resolution on rare diseases is gaining momentum, offering hope for stronger policies and improved care. In Lebanon, patient advocates have taken a major step toward securing LDL apheresis access, advocating for access to this essential treatment for patients with HoFH.

Our partners continue shaping the cardiovascular health agenda on one hand and rare disease landscape on the other through advocacy and policy efforts.

Enjoy the read and have a great weekend ahead.

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FH EUROPE FOUNDATION
NEWS

More Than You Can Imagine – Rare Disease Day through the Lens of HoFH and FCS

At FH Europe Foundation, Rare Disease Day (February 28) is a pivotal moment to shine a light on the broader challenges and solutions in rare diseases, while showcasing them through the lens of Homozygous Familial Hypercholesterolaemia (HoFH) and Familial Chylomicronaemia Syndrome (FCS)—two rare lipid disorders that deeply impact patients' lives.

With **dedicated awareness days** now in place, **HoFH on May 4th** and **FCS on**

the first Friday of November (Nov 7 in 2025), Rare Disease Day offers an opportunity to highlight the **shared struggles, systemic gaps, and potential solutions** for people living with all rare diseases.

This year, we proudly support **EURORDIS' global campaign** under the theme **"More Than You Can Imagine,"** amplifying the voices of rare disease patients worldwide. To help raise awareness, **a dedicated social media toolkit** is available in multiple languages.
Download it **here**.

Learn more about Rare Disease Day and rare conditions **here**.

Join our exclusive webinar powered by the amazing patient ambassador, a medical expert and our new team member, to hear real patient stories and explore the intersection of rare lipid disorders and broader rare disease challenges. **By showcasing lived experiences** and the **commonalitie**s among rare conditions, we aim to drive meaningful advocacy and change.

Tomorrow, February 28 – More Than You Can Imagine – Rare Disease Day through the Lens of HoFH and FCS
Register **here**.

Let's stand together to make rare diseases more visible!

A Moment of Recognition: Avery & Elisete as EURORDIS Photo Award Finalists

We are incredibly proud to share an outstanding achievement from our community. FH Europe Foundation’s Young Patient Ambassadors, Avery and Elisete, were named among 6 finalists for the prestigious EURORDIS Rare Is Beautiful Photo Award 2025, a global competition celebrating the resilience and beauty of life with a rare disease. To our great excitement, Elisete’s photo was awarded the 3rd place during the Black Pear Awards night last Monday! Each year, hundreds of photographs capturing personal journeys and raising awareness of rare conditions are submitted. From these, only a select few are chosen by award-winning photographer Marcus Bleasdale. Their participation helped shine a light on Homozygous Familial Hypercholesterolaemia (HoFH) and Familial Chylomicronaemia Syndrome (FCS), two rare lipid conditions that impact many worldwide.

Though the competition has concluded, their recognition remains a powerful moment for the community. We are incredibly proud of their accomplishments, and their stories continue to inspire, fostering greater awareness and understanding of rare diseases.

Congratulations to all the finalists!
Read more about it **here**.

Honouring Rare Disease Champions at the EURORDIS Black Pearl Awards

The EURORDIS Black Pearl Awards ceremony in Brussels brought together rare disease advocates, and it was a fantastic evening for our rare lipids community!

Representing FH Europe Foundation community in person were Athanasios (Thanos) Pallidis from Greece, a 2021 finalist and dedicated HoFH advocate, and Helga Davidson from Scotland, a new ambassador raising awareness for

FCS. They were joined by Emma Print, FH Europe's Community Engagement Manager.

Helga reflected on the evening: "It was a wonderful evening and experience. And quite humbling and inspiring listening to people's stories and how they improved their and others lives through advocacy. Thank you for giving me this thought-provoking opportunity. I learnt a lot."

Read more about it **here**.

European Parliament Event on Rare Disease Day

FH Europe Foundation team will represent the Network at the Rare Disease Day "More Than You Can Imagine" 2025 event at the European Parliament in Brussels, hosted by MEP Stine Bosse. This event, following the launch of a new European Parliament Intergroup on Cancer and Rare Diseases, aims to highlight the impact of rare diseases on individuals, families, healthcare systems, and society. With the newly appointed Rare Diseases Project Manager at FHEF, we will mark Familial Chylomicronaemia Syndrome (FCS) and Homozygous Familial Hypercholesterolaemia (HoFH) as rare diseases, contributing to discussions on policy solutions to improve care and support at the EU level.

Read more about it **here**.

A Step Forward for HoFH Patients in Lebanon

For HoFH patients in Lebanon, access to life-saving treatment has been uncertain due to ongoing crises. On February 17, 2025, Chyrel Lichaa, FH Europe HoFH Patient Ambassador, along with fellow advocates Rose Chahine and her son Marc Salloum, and Saide Salloum, met with the Presidential Office to advocate for consistent access to LDL apheresis in the country.

The meeting was the result of years of advocacy. Chyrel's efforts included participation in the World Heart Federation's White Paper on Cholesterol, international forums, and FH Europe Foundation’s HoFH Awareness Day. A formal letter co-signed by leading international experts urged the Ministry of Public Health to act.

During the meeting, Chyrel and the team presented scientific evidence and personal testimonies. The Advisor to the President assured them that their case would be escalated, with follow-up discussions planned.

Read more about it **here**.

Preparing for Lp(a) Awareness Day 2025

Lp(a) Awareness Day, taking place on March 24, is dedicated to raising awareness about elevated Lipoprotein(a) [Lp(a)], a major but often overlooked risk factor for cardiovascular disease. Launched in 2022, this annual event highlights the importance of screening, education, and advocacy to ensure better recognition and management of high Lp(a) levels.

In the lead-up to this important day, FH Europe Foundation is preparing a series of activities and resources to support awareness efforts. The official Lp(a) Awareness Campaign will begin on March 3, providing tools for individuals, organisations, and healthcare professionals to take part.

A key event in this year’s campaign is the first ever Lp(a) Global Summit, taking place on March 24–25. Scientific and medical experts, policymakers, and patient advocates will gather to discuss the latest research, policies, and strategies to improve Lp(a) recognition and patient care. The highlight of the event will be the presentation of the results of the cost effectiveness study on Lp(a) testing commissioned by the Lp(a) International TaskForce and the Brussels Declaration.

To further extend the conversation, a dedicated webinar on March 31 (18:00–19:00 CET) will summarise the key outcomes of the summit. The session will feature presentation of the Lp(a) testing cost-effectiveness study and the Brussels Declaration, two powerful tools to help advocate for early detection and CVD prevention,

With one in five people affected by elevated Lp(a) yet little awareness or routine testing, this campaign aims to bring Lp(a) into focus as a crucial but under-recognised health issue. Through education, advocacy, and collaboration, Lp(a) Awareness Day 2025 will help drive forward progress in screening, research, and policy action.

Read more and learn how to get involved **here**.
Register for the webinar **here**.

Advancing Cardiovascular Health in Europe: A Milestone under the Polish EU Presidency

FH Europe Foundation reached another milestone in its **joint efforts with the EACH community** to secure a **Cardiovascular Health Plan**. At the **Polish Cardiac Society Conference**, held under the **Polish EU Presidency, Magdalena Daccord, Agnieszka Wołczenko (ECOSerce, Poland), David Kelly (Global Heart Hub),** and **Prof. Ivan Pećin (Croatia)** represented the **familial hyperlipidaemias community.**

The conference opened with **Polish Deputy Minister for Health, Katarzyna Kacperczyk**, outlining key CVD priorities:

- Public awareness and prevention
- Addressing inequalities in access to care
- Digital health promotion
- Increased EU funding for CVD

Among key topics was **strengthening primary prevention** as emphasised by **Cecilia Linde, President-Elect of the European Society of Cardiology.**

With **Rare Disease Day approaching** and **Lp(a) Awareness Day in one**

month, the conference was a valuable opportunity to connect with **policymakers, medical experts, and patient advocates** working to improve cardiovascular health across Europe.

We would like to thank the organisers for the invitation.

Shaping the Future: FH Europe Foundation’s Strategy & Team Meeting

At FH Europe Foundation, planning for the future is a priority. In the last week of January, board members, team members, and dedicated volunteers gathered in Amsterdam for an intensive two-day strategy session to shape the long-term vision of our work and define a bold action plan for 2025.

With the recent FH-EARLY project grant and PERFECTO - FH and PerMed FH, we stand at a critical turning point. This requires clear goals, ambitious strategies, and unwavering dedication. The agenda focused on refining our mission, values, and key objectives; securing essential funding; expanding community engagement; and strengthening our organisational structure—all to create a real impact for individuals and families affected by familial hyperlipidaemias.

Beyond planning, this meeting was an opportunity to reflect on achievements from 2024, welcome new team members, and reinforce our shared commitment to driving change. The projects ahead have the potential to transform how conditions such as HeFH, FH, HoFH, elevated Lp(a), and FCS are addressed.

As always, our work is driven by the people and for the people living with these disorders. Their health and future deserve nothing less than our best efforts.

Two New Members Join FH Europe Foundation

We're excited to welcome Maja Bartoszewicz-Moritz and Magda Anthousi to the FH Europe Foundation team. Their expertise and dedication will strengthen our mission to improve the lives of those affected by inherited lipid disorders.

- **Maja Bartoszewicz-Moritz**, Project Manager for Rare Diseases, brings over 15 years of advocacy experience across Sweden, Italy, and Poland. A caregiver and patient representative, she is committed to amplifying under-represented voices and improving healthcare access.
- **Magda Anthousi**, Project Manager, has a background in chemistry, banking, and public health. Based in Cyprus, she combines research, education, and project management to support FH Europe's initiatives.

With these new additions, FH Europe Foundation continues to expand its impact and drive meaningful change.

Read more about it here.

NETWORK NEWS

Czechia - ČAKO

ČAKO released new patient brochure *Diet and cooking in the prevention of CVD*

At the request of patients and members of the patient organisation, a brochure written by an experienced nutritional therapist has been produced, which provides a detailed and practical guide to dietary composition in the prevention of CVD. What it contains: how to ensure a diet rich in quality nutrients, including protein and unsaturated fatty acids; how to put together simple recipes; how to read food packaging; how to avoid excess sugars and salt; how to enrich the diet with fish; and much more!

The brochure is also available online for free!

It’s available in Czech **here**.

France – ANHET.F

Recordings from the French Senate on FH Paediatric Screening Are Now Available!

As we shared in our October newsletter, Anhet.F held a pivotal meeting on October 22, bringing together experts and policymakers to advocate for FH paediatric screening. The recordings are now available on their YouTube channel!

You can watch it **here**.

Hungary - SZÍVSN

Successful Conclusion of the “SZÍVSN Helps Ópályi!” Campaign

In December 2024, SZÍVSN successfully completed the “SZÍVSN Helps Ópályi!” campaign, enhancing cardiovascular health among residents in deep poverty in Northern Hungary. With government support, 241 locals received comprehensive screenings, marking a step toward greater health awareness in the region.

The initiative combined education, screenings, equipment lending, and over 13 years of expertise to drive lasting change. Beyond assessments, it aimed to evaluate health literacy and foster long-term improvements.

Screenings included blood sugar, cholesterol, weight, waist circumference, blood pressure, and ECG measurements. Five volunteers facilitated the process at the local Teleház, with results shared with general practitioners for follow-up care.

The findings were alarming:

- Among 159 women: 32% had high blood pressure, 33% had high blood sugar, 19% were overweight, 30% had high cholesterol, and 9% had arrhythmias.
- Among 82 men: 55% had high blood pressure, 20% had high blood sugar, 44% were overweight, 22% had high cholesterol, and 7% had arrhythmias.

In Szolnok, SZÍVSN organised a CPR training session and hosted an engaging lecture on contraception, led by Pesthy Anna from the Budapest Medical Students' Association.

Although a small step in addressing a significant issue, the campaign has helped spark positive change in Ópályi. The ECG devices, blood sugar and cholesterol monitors, and blood pressure machines, funded by the government, will continue supporting local cardiovascular screenings and preventive care.

Read more about it here.

January 23 2025

NEW YEAR NEW YOU 43

LIFE

NEW YEAR NEW YOU!

How to thrive in 2025!

MARY O'CONNOR

'Know your numbers', it could save your life

Ireland - Croí

Raising Awareness on Inherited High Cholesterol: Croí Connects in the Media

Croí Heart and Stroke Charity in Galway, Ireland, is delighted to see Irish media highlighting vital cardiovascular health topics covered in the Croí Connects Podcast. A recent feature in the Galway Advertiser by Mary O'Connor focused on the importance of "knowing your numbers"—understanding cholesterol levels to prevent heart disease and stroke. The article emphasised the risks of inherited high cholesterol (FH), affecting 1 in 250 people, and the importance of early diagnosis and treatment. This media interest reinforces the mission of Croí Connects: to provide expert-led, accessible discussions that empower individuals to take control of their heart health.

Read the article here or listen more about it here.

NEWS
FROM AROUND THE WORLD

World Heart Assembly

A Major Milestone for Rare Diseases

Great news! The WHO Executive Board has recommended the adoption of the WHA Resolution on Rare Diseases at the 78th WHA in May. With 26 cosponsors and 224 organisations in the coalition, rare diseases are gaining well-deserved global recognition. FH Europe Foundation is proud to be part of this movement, advocating for meaningful change and improved care.

However, the resolution is not yet officially adopted—we must continue building support to ensure its approval in May. Help amplify our message by sharing updates and making the voices of People Living with a Rare Disease heard. We'll keep you updated on the next steps—let's keep pushing forward together!

Read more about it here.

PARTNER NEWS

EURORDIS

EURORDIS Rare Barometer Reveals Major Barriers to Disability Recognition and Social Participation

EURORDIS-Rare Diseases Europe has released findings from its latest Rare Barometer survey, highlighting significant barriers faced by people living with rare diseases in Europe. Conducted across 43 countries with 9,591 respondents, the survey confirms that 8 in 10 people with rare diseases live with disabilities, yet many struggle to obtain recognition and access essential support.

Key findings reveal that 57% have undergone disability assessments, but one in three did not receive the expected outcome, often due to underestimation of their needs. Over half of respondents found it difficult to access publicly funded support, and 79% of students with rare diseases face restricted participation in school. The unemployment rate for those with rare diseases stands at 23%—nearly four times the EU average.

EURORDIS calls for urgent policy action at both national and EU levels to improve disability assessments, recognition, and support systems, ensuring equal participation in education, employment, and society.

Read more about it **here**.

European Parliament Establishes New Intergroup on Cancer & Rare Diseases

The European Parliament has launched a new Intergroup on Cancer & Rare Diseases for the 2024–2029 legislature, a major step in strengthening EU efforts in these areas. The initiative, led by the European Cancer Organisation (ECO), EURORDIS-Rare Diseases Europe, and the European Society for Paediatric Oncology (SIOPE), will serve as a platform for policy discussion and advocacy.

MEP Vlad Voiculescu (Renew, Romania) has been appointed as Chair, with Vice-Chairs from across the political spectrum. The Intergroup aims to prioritise the unmet needs of people living with cancer and rare diseases, promote EU funding, and improve healthcare access. A process for external engagement will be announced soon, with initial actions including hearings on the Multiannual Financial Framework, access to treatment, and pharmaceutical legislation.

Read more about it **here**.

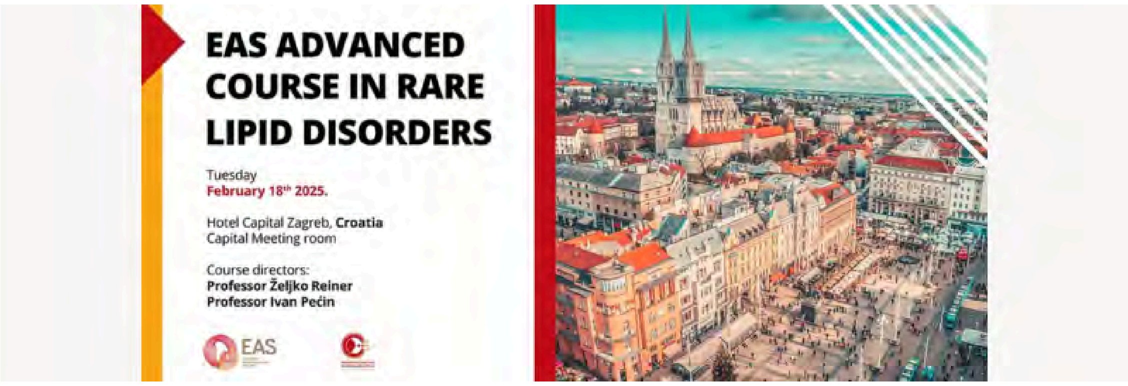
European Atherosclerosis Society - EAS

EAS AtheroTalk: Latest Insights on Lp(a) with Prof. Florian Kronenberg

The latest episode of AtheroTalk features Prof. Florian Kronenberg, a leading expert in genetic epidemiology, discussing key breakthroughs in Lp(a) research. As a key contributor to the EAS Consensus Statement on Lp(a), he explores how these guidelines are shaping clinical practice, debunks misconceptions about Lp(a) thresholds, and highlights major unanswered questions.

The episode also covers upcoming milestones in the field, including the Lp(a) International Task Force and the 1st Global Lp(a) Summit, where experts, patients, and policymakers will advocate for change. Prof. Kronenberg also shares insights into his role as Deputy Editor of Atherosclerosis Journal.

Listen to the podcast **here**.



EAS ADVANCED COURSE IN RARE LIPID DISORDERS

Tuesday
February 18th 2025.

Hotel Capital Zagreb, **Croatia**
Capital Meeting room

Course directors:
Professor Željko Reiner
Professor Ivan Pećin

EAS Advanced Course in Rare Lipid Disorders Held in Croatia

The EAS Advanced Course in Rare Lipid Disorders in Croatia provided an in-depth exploration of the diagnosis and management of these conditions. While individually rare, these disorders are collectively significant and often linked to high morbidity and mortality. Given that many clinicians may encounter such cases in their practice, the course emphasised the importance of early recognition and effective treatment.

Through real clinical cases, participants gained practical insights into evaluation and management, engaging in discussions on research findings, new treatment approaches, and expert perspectives.

Led by Prof. Željko Reiner and Prof. Ivan Pećin, the course contributed to enhancing clinical awareness and improving patient care for rare lipid disorders.

Read more about it **here**.

World Heart Federation—WHF

Ensuring Cardiovascular Care for Women and Children

At the 156th WHO Executive Board session, the World Heart Federation delivered a statement on Agenda Item 14, addressing the Global Strategy for Women's, Children's, and Adolescents' Health. Cardiovascular disease remains a leading cause of maternal death and the number one killer of women worldwide. The Federation emphasised the need for early detection and multidisciplinary care before, during, and after pregnancy.

The statement welcomed the inclusion of implementation guidance on rheumatic heart disease, a neglected CVD primarily affecting women and children. However, significant gaps persist in awareness, access, and comprehensive care. Standardised CVD care within UHC and PHC programs is essential to reduce mortality, ensuring global policies address availability and contextual needs.

Read more about it here.

Ensuring Universal Access to Safe and High-Quality Medical Products

At the 156th WHO Executive Board session, the World Heart Federation, on behalf of the Fight the Fakes Alliance, welcomed the independent evaluation of the Member State Mechanism on Substandard and Falsified Medical Products. Globally, an estimated $30.5 billion is wasted annually on such products, with WHO data indicating that 1 in 10 medicines in low- and middle-income countries are substandard or falsified, posing serious risks to health and trust in healthcare systems.

The Federation strongly supports enhanced engagement with non-state actors and urges WHO to continue its efforts to combat substandard and falsified medical products. The Alliance remains committed to working with stakeholders to ensure universal access to safe, effective, and high-quality medical products.

Read more about it here.

NEW PUBLICATIONS

Living with Elevated Lipoprotein(a) Levels: The Experiences of Patients and Caregivers

A new publication explores the experiences of individuals living with elevated lipoprotein(a) (Lp[a]), an inherited condition that increases the risk of cardiovascular disease (CVD). Despite its impact, awareness remains low, leading to delayed diagnosis and limited support.

Back in 2023, FHEF patient ambassadors participated in an online advisory board, which gathered insights from patients and caregivers through extended discussions. Outcomes of the advisory board were published with some of the ambassadors invited to coauthor it on behalf of the community. Among them was Emma Print, Janine Shipton, India Rijken and Magdalena Daccord.

Many participants reported that Lp(a) testing was often overlooked due to the lack of targeted treatment. In the absence of approved Lp(a) lowering therapies, they were advised to adopt lifestyle changes and cholesterol-lowering medications, which help reduce overall CVD risk but do not directly lower Lp(a) levels. Participants also highlighted inconsistent lifestyle advice and a lack of preventive care focus.

The findings underscore the urgent need for greater awareness, improved physician guidance, and access to reliable information to better support those affected by elevated Lp(a).

Read more about it **here**.

KNOWLEDGE HUB

Understanding AI in Healthcare: Key Takeaways from the EU’s AI Act

The European Commission has released guidelines to clarify what qualifies as an Artificial Intelligence (AI) system under the new AI Act. These guidelines help companies and individuals determine if their software falls under AI regulations, ensuring safer and more ethical AI use while fostering innovation.

The guidelines explain what an AI system is, help users assess whether their software qualifies, and outline different risk levels—some AI applications are even banned due to unacceptable risks. The framework is flexible and will evolve based on new developments.

Why This Matters to our Community

AI is playing a growing role in healthcare, including FH diagnosis and treatment. Understanding these guidelines ensures compliance with EU regulations while protecting patient data and privacy. It also strengthens our advocacy for fair, transparent, and accountable AI in healthcare.

Staying informed helps us balance innovation with compliance, opening doors to funding and partnerships with organisations committed to ethical AI. By integrating these guidelines, FH Europe Foundation continues to amplify the patient voice and advance awareness, diagnosis, and treatment of inherited lipid conditions.

Read more about it **here**.

SAVE THE DATE

- **February 28 –** Rare Disease Day
- **March 4 –** World Obesity Day
- **March 5 –** European Parliament Event on Rare Disease Day
- **March 8 –** International Women´s Day
- **March 24 –** Lp(a) Awareness Day
- **March 28 -** National Triglycerides Day (US)
- **April 10-11** – Amb. Prog. Training, Cyprus
- **May 4** – HoFH Awareness Day
- **May 17-18** – World Heart Summit, Switzerland
- **November 14-16** – FH Europe Foundation Annual Meeting, Croatia

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