
Welcome to the February 2026 edition of Heart Beat News



Heart Beat News

2 March 2026

February has been a month of remembrance, advocacy, and renewed momentum across our community. From international assemblies to local awareness campaigns, this edition highlights the collective action driving earlier detection, equitable care, and stronger patient representation in familial hypercholesterolaemia and rare lipid disorders.



*With deep respect, we honour Véronique Lemaître, founder of ANHET.f and a dedicated advocate who transformed personal loss into meaningful action for the community in France and across Europe. Her commitment to awareness, early diagnosis, and patient voices continues to inspire our work. We invite you to read the **full tribute** and learn more about the legacy she leaves behind.*

FH EUROPE FOUNDATION NEWS



Rare Disease Day

On Rare Disease Day, we reaffirmed the importance of equitable access to diagnosis, treatment, and lifelong care for people living with rare lipid disorders, such as homozygous FH and FCS, across Europe and beyond. This year, we strengthened support for patients and communities through practical resources, including our updated [website](#) and advocacy toolkit, and continued to raise awareness across channels. We also spotlighted the lived experiences behind the statistics through powerful interviews with [Joanna](#) and [Manfred](#), who shared their personal journeys, offering insight into the daily realities, challenges, and resilience of those living with rare conditions. In addition, Marina Leroy, our Communication Manager, joined a Rare Disease Day webinar, organised by the European Synthetic Biology Society, as a speaker, helping further amplify the patient voice.

Lp(a) awareness day & community call

Lp(a) awareness day is approaching (24 March), shining a spotlight on lipoprotein(a) as an independent and genetically determined risk factor for cardiovascular disease. This important milestone is an

COMMUNITY CALL

for the

Lp(a) Awareness Day 2026

 Thursday, 5 March



Register for
13.00 CET



Register for
18.00 CET

opportunity to raise awareness about the need for early testing, informed conversations with healthcare professionals, and improved access to appropriate care across Europe. To mark the occasion, we will also host dedicated community calls on Thursday, **5 March 2026**, at **13:00** and **18:00 CET**.

[Register here to attend the 13.00 call](#)

[Register here to attend the 18.00 call](#)

A wonderful night at the EURORDIS Black Pearl Awards 2026!

Elsie Evans represented FH Europe Foundation at the **EURORDIS Black Pearl Awards** in Brussels, an evening that embodied the strength, solidarity and forward momentum of the rare disease community. From transformative policy leadership and AI-powered diagnostic innovation to meaningful patient engagement and grassroots advocacy, this year's awardees demonstrated how systemic change is achieved when expertise aligns with lived experience. Particularly powerful were the moments led by young ambassadors and public-voted winners, reinforcing the impact of authentic patient voices. Representing the HoFH and FCS community, Elsie proudly highlighted our collective commitment to advancing awareness, equity and action across Europe.



Thank you to  and all Speakers



From Evidence to Everyday Life: Understanding the ESC–EAS Dyslipidaemia Guidelines
The webinar trilogy

Dyslipidaemia webinar series: recordings and follow-up

We would like to warmly thank all our speakers and participants for contributing to our recent webinar series, as well as EAS for the endorsement. Your expertise, thoughtful questions, and active engagement made these sessions both informative and meaningful for our community. Recordings are already available on our [YouTube channel](#), and we will soon share responses to the questions that could not be addressed live. Thank you for your patience and continued interest.

AMBASSADORS NEWS

Learning and connection at the Action FCS Patient & Carer event



Ambassadors—Helga Davidson, Devon and Finnian Day-Lewis, Teevi and Elisete Pobus, Elsie Evans—recently attended the [Action FCS](#) Patient & Carer event in Birmingham, where experts and community members shared practical insights on nutrition, mental well-being, and the latest developments in FCS. The day offered valuable learning and meaningful connections.

Bringing the HoFH Community together at London Zoo

Our Ambassador Elsie Evans also attended the **HEART UK** HoFH Family day at London Zoo, a meaningful gathering that brought together families, individuals living with HoFH, and advocates for a day of learning, connection, and shared experiences. The event combined practical education, inspiring personal stories, and open discussions about ongoing challenges in care, highlighting the importance of community support and patient advocacy. Elsie's participation reflects our continued commitment to strengthening connections within the HoFH community and amplifying the voices and experiences of those living with rare lipid conditions.



RESEARCH PROJECTS



FH Early Annual Assembly



On 29–30 January 2026, the **FH EARLY** Consortium met in Lisbon for its Annual General Assembly, kindly hosted by CCUL (Centro Cardiovascular da Universidade de Lisboa). Partners from across Europe gathered to review project progress, exchange scientific insights, and align on upcoming milestones. The meeting highlighted important advances in personalised approaches to FH, including developments in genetic variant characterisation, cellular analysis platforms, and coordinated patient sample collection. The discussions reinforced the strength of cross-border collaboration and our shared commitment to improving early detection, diagnosis, and care for people living with FH.



Join us to Prevent the Preventable in Brussels on 27–28 April 2026 (hybrid)

“Advancing Screening for Inherited Lipid Disorders: Untapped Potential for Safe Hearts Plan in Europe”

After 30 months of implementation, the [PERFECTO](#) Project culminates in a high-level European policy and implementation forum held under the auspices of the Cyprus Presidency of the Council of the European Union.

But this event is about much more than project closure. It is a forward-looking European platform bringing together policymakers, clinicians, patient leaders, researchers, payers and EU stakeholders to accelerate action on:

- Systematic screening for Familial Hypercholesterolaemia (FH), including HoFH
- Elevated lipoprotein(a) [Lp(a)]
- Tackling inherited lipid disorders as a strategic pillar of cardiovascular prevention
- Delivering on the emerging Safe Hearts Plan

Across two days, discussions will move from policy to practice—translating evidence into implementation models, addressing inequalities, and aligning national cardiovascular health strategies with EU priorities. With participation from EU institutions, Member States, OECD, WHO, MEPs and national screening leaders, this event directly supports the EU’s Strategic Agenda 2024–2029 ambition to strengthen health cooperation, resilience and prevention across Europe. Cardiovascular disease remains Europe’s leading cause of death. Many cases are preventable. Early screening and detection are no longer optional—they are essential. Be part of the movement shaping Europe’s Safe Hearts future. This is not to be missed. More details and registration opening soon. For more details, contact anthousi@fheurope.org



PerMed FH in the Spotlight

The [PerMed FH](#) project has recently been featured in [Clarín](#) and in the “Mentes Brillhantes” section of [Observador](#), with Mafalda Bourbon highlighting its contribution to advancing precision medicine in FH. By integrating genetics, clinical data and innovative tools, PerMed-FH aims to enable earlier identification, starting in childhood, and more personalised, effective treatment strategies. The project represents a significant step toward translating research into tangible improvements in FH care.

NETWORK NEWS

Austria: FHchol Austria

FHchol Austria hosts celebratory FH Festsymposium in Vienna

[FHchol Austria](#) welcomed around 150 participants at the [FH Festsymposium](#) on 20 February 2026 at Vienna’s Billrothhaus, honouring Prof. Kurt Widhalm’s 80th birthday. Experts shared practical updates on diagnosis, treatment and prevention of FH and elevated Lp(a), stressing

early detection. Patient voices, including Verena Kozmann and Lena Rosa Hanauer, highlighted the importance of timely identification and care.

Czechia: CAKO

CAKO signs a Memorandum of Understanding with ILEP

[Czech Alliance for Cardiovascular Disease \(CAKO\)](#) has signed a Memorandum of Understanding with the [International Lipid Expert Panel \(ILEP\)](#) to advance prevention of cardiovascular and other noncommunicable diseases. The non-binding agreement supports joint research, education and policy action on lipid disorders, including elevated Lp(a), and strengthens cooperation on prevention programmes, expert guidance and advocacy at the European and international level.

Netherlands: Stichting VrouwenHart

5 years of Stichting VrouwenHart: From Patient Experience to Structural Change



The [Stichting VrouwenHart](#) marked its 5-year anniversary in The Hague with a powerful reflection on progress and persistent gaps in women's heart care. While achievements were celebrated, the message was clear: too many women still face missed or dismissed symptoms and delayed diagnosis. Too often, outcomes depend on where you live and enter the system. Women's heart health is not niche; it shapes families, workplaces and health systems, and must be embedded in care, research and policy.

Spain: Familial Hypercholesterolaemia Foundation

XI Symposium on Familial Hypercholesterolaemia: Data Value in Personalised Medicine

The [Familial Hypercholesterolaemia Foundation](#) will host its XI Symposium on **12–13 March 2026 in Madrid, Spain**. This is the only meeting in Spain dedicated to healthcare professionals who are interested in finding solutions to reduce the burden of cardiovascular disease in people with inherited lipid disorders, including heterozygous and homozygous FH and elevated Lp(a). It also provides relevant data extracted from the real-world evidence collected on [SAFEHEART Study](#), which began 22 years ago. More information and registration available [here](#).

European Society of Cardiology (ESC)

Shaping the Future of Prevention through AI and Data

FH Europe Foundation, represented by Magda Anthousi, EU Projects Manager, took part in the conference “Advancing Prevention and Equity through AI and Digital Transformation” in Nicosia, Cyprus. Organised by the Cyprus Society of Cardiology with support from the European Society of Cardiology, under the framework of the Cypriot Presidency, the event focused on prevention, high-quality data, and the responsible use of AI in cardiovascular health—key areas that align with our work in initiatives like [PERFECTO](#) and [FH EARLY](#) to advance early detection, screening, and data-driven strategies for inherited lipid disorders.

European Patients’ Forum (EPF)

EU Competitiveness Roundtable: Putting Patients at the Heart of a Competitive Europe

On 11 March 2026 (09:00–13:30), patient organisations from across Europe will gather in Brussels and online for the EU Competitiveness Roundtable, “Building the Case Together – Putting Patients at the Heart of a Competitive Europe.” The hybrid event will explore how geopolitical shifts, regulatory developments, and EU health and life sciences policies influence access to innovation and patient care. Through insights from policy and patient leaders, including representatives from EPF and other advocacy groups, participants will engage in solution-focused discussions to strengthen collective patient advocacy in an evolving European landscape. [Register now](#) to join the conversation.

EURORDIS

Interactive webinar for Patient organisations

EURORDIS is hosting an interactive webinar on 4 March (15:00–16:30 CET, online) focused on how patient organisations can help safeguard access to essential treatments through engagement with the Union List of Critical Medicines. Led by François Houÿez, Director of Treatment Information and Access, the session will provide practical insights on contributing effectively to consultations and influencing policy discussions. If strengthening access to treatment is a priority for your community, this is a valuable opportunity to get involved. [Register here](#).

NEWS FROM AROUND THE WORLD

Croatia

Hunting the Silent Killer at Samobor Carnival

At the 200th **Samobor Carnival**, the [Croatian Hypertension League](#) turned celebration into





prevention. As part of the “Hunting the Silent Killer” campaign, 30 medical students symbolically battled hypertension and cholesterol in front of 5,000 spectators. The *Lovomobil* and a 10-minute stage programme highlighted blood pressure, lipid disorders, and early detection. With support from rally driver **Juraj Šebalj**, key messages reached a broad, non-medical audience in an engaging way. Read more and watch the video [here](#).

KNOWLEDGE HUB

Online Session “Right to Innovation: Understanding Personalised Prevention”

 Tuesday, 10 March 2026

 15:00–16:30 CET

 Online (Zoom)

This session, organised within the EU [project PROPHET](#), is an interactive discussion that explains personalised prevention in clear terms, focusing on delivering the right care at the right time based on genetics, medical history, environment and lifestyle.

With practical examples in breast cancer, cardiovascular risk and pharmacogenomics, as well as lived experience, the session offers valuable insights for our community. Learning together strengthens our shared voice for earlier detection, better care and stronger prevention policies across Europe. [Register here](#).

SAVE THE DATE

- 4 March: [World Obesity Day](#)
- 8 March: [International Women’s Day](#)
- 24 March: [Lp\(a\) Awareness Day](#), FH Europe Foundation
- 7 April: [World Health Day](#), World Health Organisation (WHO)

- **27 - 28 April: Prevent the Preventable: Accelerating Action on Inherited Lipid Disorders to Power Europe's Cardiovascular Health and Competitiveness, [PERFECTO](#), Brussels, Belgium and online**
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