
Welcome to the March 2026 edition of Heart Beat News



Heart Beat News

31 March 2026

Lp(a) Awareness Day once again marked a key moment in FH Europe Foundation's annual calendar, reflecting the growing global momentum around awareness, engagement, and action on inherited lipid conditions. Building on this energy, we now look ahead to important upcoming moments, including the **PERFECTO closure event** in April and **HoFH Awareness Day** in May, continuing to strengthen collaboration, amplify patient voices, and drive progress in cardiovascular prevention.

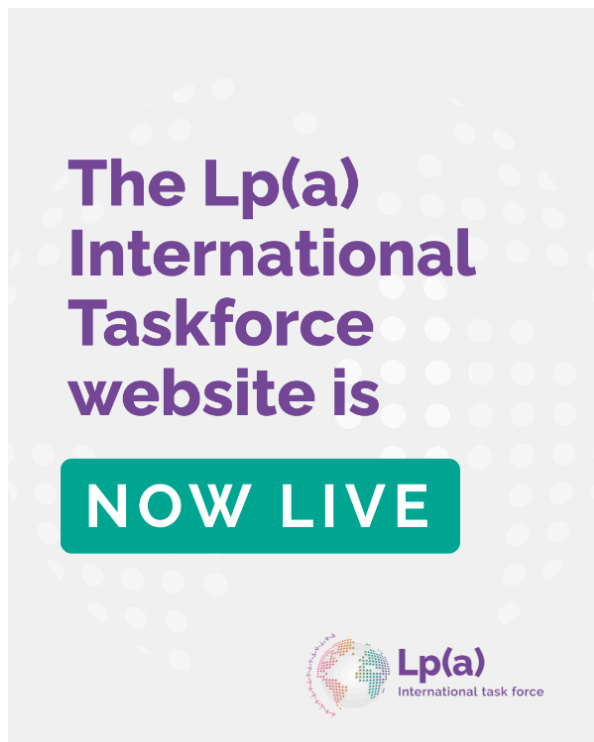
FH EUROPE FOUNDATION NEWS



Lp(a) Awareness Day: a successful campaign

We're incredibly grateful for the energy, engagement, and sense of shared purpose that made Lp(a) Awareness Day so impactful this year. The buzz across the community was truly inspiring, from the widespread use of the **toolkit** (and a heartfelt thank you again to everyone who supported and contributed to the translations), to the thoughtful **videos** and the many personal **stories** courageously shared. Your voices are what bring this movement to life, helping raise awareness and drive understanding of Lp(a) in ways that truly matter. **Thank you for showing up, speaking out, and standing together.**

Lp(a) International Taskforce



One year after [the Global Summit](#), this year's Lp(a) Awareness Day marked another important milestone: the International Taskforce officially launched its communication channels, including a brand-new [website](#), **social media** presence, and a fresh **visual identity**.

We invite you to explore these new platforms, discover the latest updates, and stay connected with the growing global effort to raise awareness and drive action on Lp(a). Follow along on social media, engage with the content, and help us amplify the message even further.

[LinkedIn page](#)
[Bluesky](#)

FOKUS event

FH Europe Foundation was proud to contribute to FOKUS Patient Future Days 2026 in Stockholm, a key forum shaping the future of healthcare in Europe. As Sweden develops its national cardiovascular plan, discussions emphasised the importance of integrating patient perspectives early, especially in areas such as dyslipidaemia, including FH and elevated Lp(a).



The session highlighted how initiatives like **FH-EARLY** and **PERFECTO** can drive earlier detection, improved care, and stronger prevention, while reinforcing the need for meaningful patient involvement in policy and implementation. [Watch the session recording.](#)

Food for Thought session at Roche Diagnostics headquarters

On the occasion of Lp(a) Awareness Day, our CEO, Magdalena Daccord, contributed to a “Food for Thought” session at Roche Diagnostics headquarters, where the **patient voice** took centre stage from the very beginning. In a powerful and engaging format, a personal story was shared through a live interview with Martin Guss, bringing to life the reality of Lp(a) risk in a way that data alone cannot.

The discussion highlighted how lived experience can make cardiovascular risk more tangible and inspire action. As one key takeaway noted, **knowing is a privilege and an opportunity to act**, underscoring the importance of raising awareness around Lp(a) and overall cardiovascular risk.



SAFEHEART & Beyond – Croatian Model event

At the [SAFEHEART & Beyond – Croatian Model forum](#), stakeholders from across Europe came together to push cardiovascular prevention from policy into practice, with a strong focus on **early detection**, **community-based action**, and **reducing regional inequalities**. Representing the FH Europe Foundation, Magdalena Daccord, our CEO, underscored the importance of placing patients and society at the centre, advocating for a life-course approach with early diagnosis, lifelong management, and equitable access to care, using familial hypercholesterolaemia as a model. With growing national momentum, including Croatia’s

leadership on paediatric screening and prevention, the challenge now is clear: turn commitment into coordinated action at scale.

AMBASSADORS NEWS

5th Heart Failure Roundtable in Nuremberg



Renate Kaal-Poppelaars represented FH Europe Foundation and **Stichting VrouwenHart** at the 5th Heart Failure Roundtable in Nuremberg, organised by **Herzschwäche Deutschland e.V.** She brought a strong patient perspective, highlighting under-recognised aspects of **women's cardiovascular health**, including ANOCA, microvascular dysfunction, and elevated Lp(a). Her contribution reinforced the need to better recognise women's symptoms and the vital role of patient voices in improving awareness, diagnosis, and care.

SIGLipid event

Elsie Evans, Patient Ambassador and Ambassador Programme Manager, recently contributed to the **SIGLipid event for lipid-focused nurses in Denmark**, organised by Berit Storgaard Hedegaard. She highlighted the key role nurses play in supporting people with inherited lipid disorders and the importance of patient education in improving outcomes. By sharing lived experience, Elsie demonstrated how patient voices can strengthen nursing education and patient-centred care.



World Adherence Day

As part of World Adherence Day, we were proud to see our ambassador, **Renate Kaal-Poppelaars** contribute to the global conversation by speaking at a related event. Her perspective brought a powerful and personal dimension to the discussion, highlighting the **real-world**

importance of adherence in managing cardiovascular health. By sharing her experience and insights, Renate helped reinforce why patient voices are essential in shaping more effective, compassionate approaches to care. We thank her for representing our community and helping to amplify this important message.

Dutch CardioVascular Alliance meeting in the Dutch Parliament



Just one day after Lp(a) Awareness Day, our ambassador **Marc Rijken** spoke at the **Dutch CardioVascular Alliance meeting in the Dutch Parliament**, where key stakeholders gathered to advance **implementation of the EU Safe Hearts Plan**. Marc shared his personal journey with cardiovascular disease—despite a healthy lifestyle, his condition went unrecognized for years until elevated Lp(a) was identified—highlighting critical gaps in awareness and early detection. Today, he continues to turn his experience into impactful advocacy, helping drive progress toward better screening, prevention, and care across Europe.

RESEARCH PROJECTS



Registration open for the PERFECTO closure event

Registrations are now open for PERFECTO's high-level April event in Brussels, held under the auspices of the Cyprus Presidency of the Council of the European Union, marking a pivotal moment for advancing cardiovascular prevention in Europe. Bringing together leading voices—including representatives from the **European Commission, WHO, and patient ambassadors**, with first speakers now announced—the event will spotlight paediatric screening for familial

hypercholesterolaemia as a gateway to early detection and implementation at scale.

Strongly supported by organisations such as [European Alliance for Cardiovascular Health \(EACH\)](#), [European Atherosclerosis Society \(EAS\)](#), [International Atherosclerosis Society \(IAS\)](#), and [Global Heart Hub \(GHH\)](#), it reflects broad alignment across policy, science, and the patient community to move from evidence to action.

Check the agenda and register [here](#)

Registration open

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

27-28 April 2026
Brussels, Belgium (Hybrid)

perfecto
Powering the Profession

CY2026.EU

Co-funded by the European Union

Endorsed by

each
European Alliance for Cardiovascular Health

EAS
European Atherosclerosis Society

INTERNATIONAL
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SOCIETY

Global Heart Hub

NETWORK NEWS

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Patient Network
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Lp(a) Awareness Day 2026

March 24 2026

Online Campaign

China: FH China

A Month of Strong Progress in Advocacy and Research

FH China has demonstrated strong renewed momentum this month through a range of impactful initiatives. Notably, they launched “*Just Like You*,” the first FH China **Choir song**, helping to amplify patient voices and awareness through a creative medium. In parallel, they actively engaged in online campaigns for **Rare Disease Day** and **Lp(a) Awareness Day**, further strengthening public outreach and education. Complementing these efforts, FH China advanced

important **research** by conducting 15 patient interviews focused on the **psychological impact of delayed diagnosis in HoFH**, contributing valuable insights to better understand and support the patient experience.

Czechia: CAKO

CAKO signs a Memorandum of Understanding with ILEP

ČAKO, together with the Czech Society of Cardiology, hosted a roundtable at the **Chamber of Deputies** to advocate for expanding nurses' roles in cardiology. They also announced a **new professional society for care coordination**, aiming to standardise the coordinator role and improve continuity of care for patients with complex cardiovascular conditions.

Netherlands: HartStichting

A Bigger, Louder Community Voice: Harteraad Joins Forces with Hartstichting



Harteraad, the Dutch patient organisation for people with heart and vascular conditions and a member of the FH Europe Foundation Network, has officially joined **Hartstichting**. This positive step unites two strong voices, strengthening outreach, advocacy, and the impact of patient perspectives in shaping the future of cardiovascular care and prevention.

Greece: LDL Greece

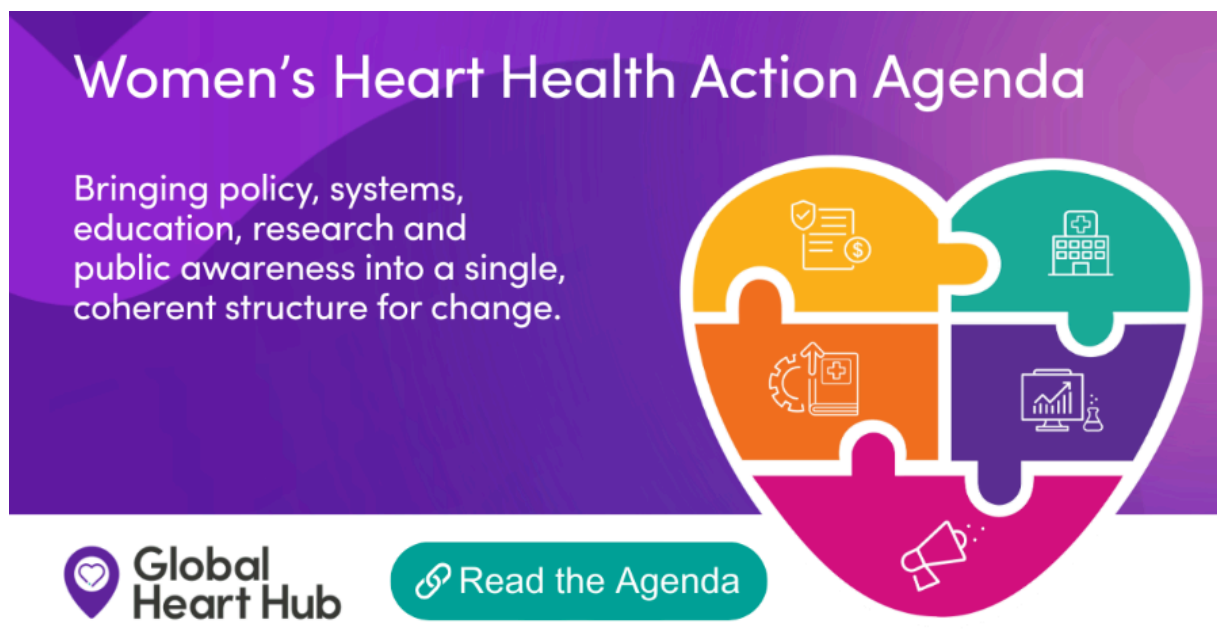
Raising Awareness Through Media and Medical Engagement

LDL Greece has demonstrated strong engagement through both **media outreach** and **collaboration with the medical community**. For **Rare Disease Day**, members of the association were featured on national TV (ERT3), sharing patient and caregiver experiences of living with HoFH alongside expert insights on the importance of early diagnosis and treatment. Building on this visibility, LDL Greece will also participate in an upcoming **seminar in Thessaloniki**, where they will present their work, share the patient perspective with healthcare professionals, and contribute to panel discussions, further underscoring the importance of patient advocacy in shaping the understanding of FH.

Spain: Familial Hypercholesterolaemia Foundation

Dr. Pedro Mata, President and Founder of the Spanish Familial Hypercholesterolaemia Foundation has been nominated in the Medicine category of the *Diario Médico Admirable Awards*. A leading expert in familial hypercholesterolaemia and Director of the SAFEHEART study, his work has

significantly advanced research and care—community members are encouraged to support his nomination by voting [here](#).



The graphic features a purple background with a large heart shape composed of five interlocking puzzle pieces in yellow, orange, teal, purple, and pink. Each piece contains a white icon: a shield with a dollar sign, a hospital building, a gear with a plus sign, a bar chart with a flask, and a megaphone. To the left of the heart, the text reads: 'Women's Heart Health Action Agenda' in white, followed by 'Bringing policy, systems, education, research and public awareness into a single, coherent structure for change.' in white. At the bottom left is the 'Global Heart Hub' logo (a purple heart with a white outline) and the text 'Global Heart Hub'. To the right is a teal button with a white link icon and the text 'Read the Agenda'.

Global: Global Heart Hub

Women's Heart Health Action Agenda launched

Global Heart Hub has launched its Women's Heart Health Action Agenda, a comprehensive framework aligning policy, systems, education, research, and awareness to improve outcomes for women globally. Co-created with patients and clinical experts, it provides a clear, actionable pathway for change.

[Read the Action Agenda now.](#)

PARTNER NEWS

European Society of Cardiology (ESC)

New patient version of ESC Guidelines on pregnancy

Marking **International Women's Day**, the European Society of Cardiology (ESC) highlighted the need to better support women living with cardiovascular disease, including through [new patient-focused guidance on pregnancy and heart health](#). The initiative emphasises informed decision-making, multidisciplinary care, and earlier specialist support—critical steps given that a large proportion of pregnancy-related cardiovascular deaths are preventable.

EP Permed

Podcast The Science of You

In the last episode of EP PerMed's podcast *The Science of You*, the story of Olivia and Dianne shows how **early diagnosis and personalised treatment** can transform lives from childhood. As Magdalena Daccord noted, it's a powerful example of how precision medicine is reshaping cardiovascular care and improving patient outcomes. [Listen to the podcast](#)

World Heart Federation (WHF)

WHF Roadmap Integrated Care

The World Heart Federation's new roadmap calls for an urgent shift toward **integrated, person-centred care** for people living with—or at risk of—cardiovascular disease and multiple long-term conditions. It emphasises that aligned policies, shared leadership, patient and community engagement, and targeted investment, particularly in primary care, are essential to build more equitable and resilient health systems. [Read more here](#).

NEWS FROM AROUND THE WORLD

New US guidelines on dyslipidaemia management

New guidelines published in *Circulation* by the [American Heart Association \(AHA\)](#) and [American College of Cardiology \(ACC\)](#) provide updated, comprehensive recommendations for the management of dyslipidaemia, covering evaluation, treatment, and long-term monitoring. With a **strong emphasis on patient-centred care**, the guidance reinforces the role of lipid management—including cholesterol, triglycerides, and other risk factors—as a cornerstone of cardiovascular disease prevention and risk reduction. [Read them here](#)

KNOWLEDGE HUB

FHEF Dyslipidaemia webinar trilogy: follow up

Following our recent dyslipidemia guidelines webinar trilogy, we're pleased to share that **answers** to the questions we couldn't address during the [live Q&A sessions](#) are now available.

In response to strong interest from the community, we are also compiling **local guidelines and consensus papers on dyslipidaemia management**, accessible on a dedicated page of our [website](#). We already have guidelines available from China, France, Luxembourg, the Netherlands, Portugal, Spain, the UK, and the USA, and we warmly invite experts to help guide us toward additional relevant documents. We hope these resources will provide continued support and practical guidance in this area.

EUDF – Know your numbers

The [European Diabetes Forum \(EUDF\)](#) will hold a webinar, “*Know Your Numbers: The Importance of Health Checks in the Safe Hearts Plan,*” on **6 May from 12:00–13:00 CET** (via Zoom). The session will highlight the importance of **early detection in diabetes and cardiometabolic conditions**, present the new EU health checks protocol, and share practical insights on implementation, including childhood screening. [Register here to join.](#)

Global Heart Hub – Clinical research resources

Global Heart Hub has launched a Clinical Research Initiative, including a Clinical Trials Portal and patient-friendly educational resources to help patients better understand and access clinical research. [Read more.](#)

SAVE THE DATE

- 7 April: [World Health Day](#), World Health Organisation (WHO)
 - 19 April: [World Liver Day](#), global liver societies
 - 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
 - 4 May: [HoFH Awareness Day](#), FHEF
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