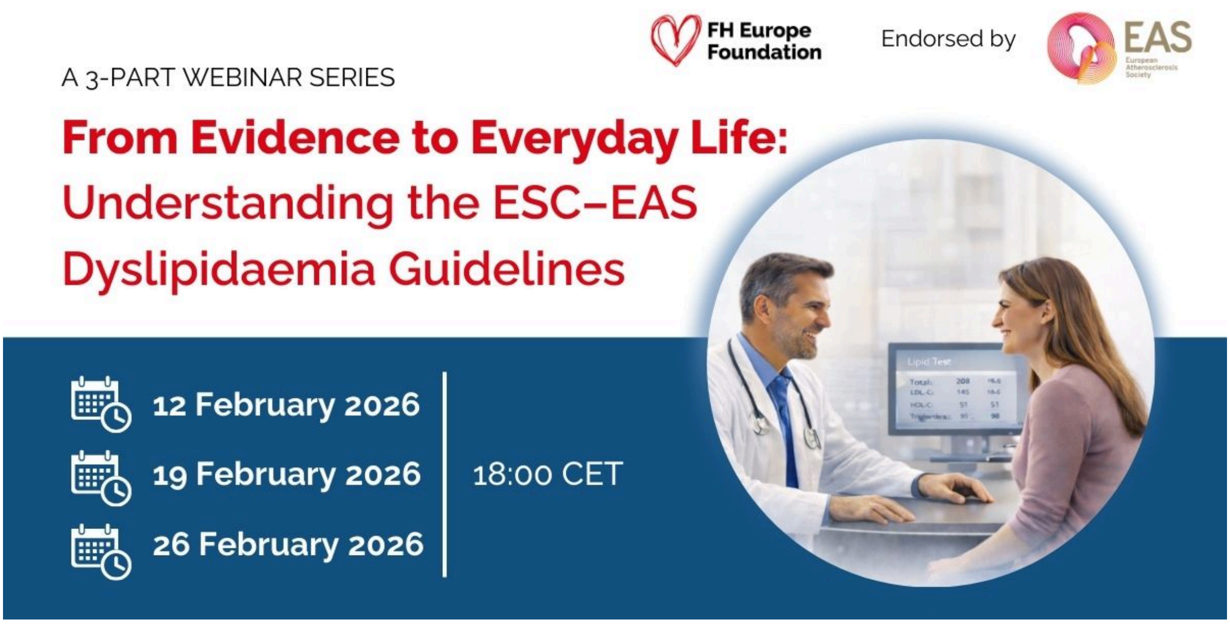
FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

30 January 2026

2026 is already proving to be an intense and energising year, and we’re only just getting started. There’s a lot ahead—from our upcoming webinar series in February to a high-level in-person event in April—and even more taking shape behind the scenes. At the heart of it all is our community: your ideas, your energy, and your ambition continue to push us to do more, and to do it with you and for you. We’re excited about what’s coming and grateful to be building it together.

FH EUROPE FOUNDATION NEWS



FH Europe Foundation

Endorsed by EAS European Atherosclerosis Society

A 3-PART WEBINAR SERIES

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

12 February 2026
19 February 2026
26 February 2026

18:00 CET

Dyslipidaemia Guidelines

This February, FH Europe Foundation is organising a free, three-part webinar series designed to help patients, caregivers, and advocates better understand the ESC–EAS Dyslipidaemia Guidelines and what they mean in everyday life. The webinar trilogy will explain how guidelines are developed, unpack the key recommendations of the 2019 guidelines, and highlight what's new in the 2025 focused update. With expert insights, patient voices, and live Q&A, the series supports informed, shared decision-making in dyslipidaemia care across Europe.

Read more and register for the webinars here.

IHU ICAN (Paris)

During the IHU ICAN colloque in Paris, discussions on cardiometabolic disease prevention highlighted the need for more dynamic, patient-centred research models. In his overview of ongoing cardiovascular research, Dr. Antonio Gallo notably referenced FH-EARLY as a key European initiative shaping early prevention in familial hypercholesterolaemia. Our CEO, Magdalena Daccord, shared perspectives on the role of patient-led innovation and collaboration, while Lionel Ribes, President of ANHET.f, one of our network members, also spoke during the event. Taking place shortly after the publication of the **EU Safe Hearts Plan**, the exchanges reflected growing momentum to better align research, policy, and patient engagement across Europe.

Awareness Days and Events Calendar 2026

FH Europe Foundation

🟥 Key Awareness Days and Events

🟦 Relevant Awareness Days and Events

▫ Nice to Know!

2026 is taking shape—and here are the dates to know. Our 2026 community calendar is ready, highlighting key dates and milestones across the year. This includes major awareness days, international and regional congresses, and upcoming FHEF events that matter to our community. We hope this overview helps you plan ahead, stay engaged, and take part in the moments that connect, inform, and strengthen our collective work throughout 2026.

Rare Disease Day 2026

On 28 February, we will join the global Rare Disease Day initiative to stand with members of our community living with rare conditions such as homozygous familial hypercholesterolaemia (HoFH) and familial chylomicronaemia syndrome (FCS). Rare Disease Day is an important opportunity to highlight ongoing challenges around equity and access to diagnosis, care, and treatment—issues that continue to disproportionately affect people with rare diseases. Despite scientific progress, significant disparities remain across countries and healthcare systems. By taking part, we aim to amplify patient voices and reinforce the need for fair, timely, and equitable access to care for everyone affected by rare conditions.

We'll be sharing more content and updates soon—keep an eye on our website and social channels. Learn more.

AMBASSADORS NEWS

Black Pearl Award

We are excited to be part of the upcoming **EURORDIS Black Pearl Awards**, an inspiring evening celebrating dedication and leadership across the rare disease community. Our own **Elsie Evans** will be representing our team, bringing her unwavering commitment to the community. We look forward to building stronger connections and continuing our collaboration with the broader rare disease ecosystem.

Can't make it in person? No worries! Tune in online for free.

From Experience to Education - bringing the patient perspective

We are delighted that our Certified Ambassador **Patsy Petrie** continues to champion the patient voice through her involvement in clinician-education initiatives that strengthen patient-centred practice. Patsy's wider public advocacy for better, more systematic patient involvement in healthcare training remains an important part of our communities ongoing commitment to ensuring that all

ensure we build solutions with the people living with FH and related conditions, not just for them.

Photo: Patsy receiving her award at the FHEF Annual Network Meeting 2025, in recognition of her outstanding commitment as a Patient Ambassador.

Sharing knowledge locally

This month also featured inspiring local innovation in the Netherlands, where Hart in Shape hosted an educational webinar on **lipoprotein(a)** (*Lp(a)*) with internationally recognised lipid expert **Prof. Dr. Erik Stroes**, delivered in collaboration with FH Europe Foundation. In this session, our amazing Ambassadors **Marc Rijken** and **Annelies Dol** shared powerful lived-experience perspectives on elevated Lp(a) and its impact on daily life, helping bring essential patient insight into a medically complex topic. **This is just the start of more local activities in local languages.**

WEBINAR

Georganiseerd door:

FH Europe Foundation

hart in shape

Verhoogd lipoproteïne (a) - Lp(a)

Uitgelegd door een expert en ervaringsdeskundigen

Prof dr Erik Stroes
Amsterdam UMC

Annelies Dol
Ervaringsdeskundige

Marc Rijken
Ervaringsdeskundige

donderdag 15 januari
19.30 - 20.30 pm (CET)
Online
www.hartinshape.nl

RESEARCH PROJECTS

FH EARLY General Assembly

The FH-EARLY General Assembly is taking place on 29 and 30 January 2026 in Lisbon, Portugal, hosted by the Lisbon School of Medicine. As the project's primary decision- making forum, the General Assembly brings together one representative from each project partner to review overall progress, discuss scientific results and implementation challenges, and agree on the strategic direction of the project. This annual meeting is key to ensuring alignment across work packages, effective coordination among partners, and the timely delivery of FH-EARLY's objectives.

PERFECTO discussed on Romanian radio

On 13 January, Dr. Marius Geantă appeared on the Romanian radio programme **Știința360** to discuss recent European developments in cardiovascular health. He addressed the newly

States. Dr. Geantă also referred to European research initiatives such as the PERFECTO project on early identification of inherited cardiovascular risk, emphasising the role of personalised prevention, research, and innovation in reducing disparities and improving outcomes. **Watch the recording here**.

PERFECTO Project Final Event - SAVE THE DATE

After 30 months of implementation, the **PERFECTO** Project will culminate in a **high-level final event** on **27–28 April 2026 in Brussels** (hybrid), held under the auspices of the Cyprus Presidency of the Council of the European Union. Designed as an open, forward-looking European forum, the event will go beyond project closure and welcome a broad range of stakeholders to engage with PERFECTO's results. Discussions will focus on translating evidence into real-world practice, advancing early and personalised prevention, addressing FH and elevated lipoprotein(a), and contributing to the EU's emerging Safe Hearts Plan. More details and registration coming soon.

SAVE THE DATE
3 months to go

Prevent the Preventable:

Accelerating Action on Inherited Lipid Disorders to Power Europe's Cardiovascular Health and Competitiveness

PERFECTO Project Final Event
under the auspices of the Cyprus Presidency
of the Council of the European Union

27–28 APRIL 2026
Brussels, Belgium | Hybrid

FH EARLY

perfecto
Preventing the Preventable

FH EARLY and PERFECTO consortia statement on Safe Hearts Plan

Following the publication of the **EU Safe Hearts Plan**, the PERFECTO and FH EARLY consortia issued formal statements welcoming the European Commission's first comprehensive framework for cardiovascular health. Both projects are explicitly referenced in the Plan, reflecting their contribution to advancing early detection and prevention of inherited cardiovascular risk, particularly familial hypercholesterolaemia. In their statements, the consortia emphasised the importance of coordinated European action, personalised prevention approaches, and the integration of research evidence into policy. They also highlighted the need to translate strategic commitments into concrete implementation, ensuring equitable access to early diagnosis and care for people at risk across all Member States.

Read the full statements here: FH EARLY **and** PERFECTO

Austria: FHchol Austria

FHchol Austria Joins GoRed Austria Campaign

FHchol Austria will be actively participating in the **GoRed Austria campaign** to raise awareness of women’s heart health and the often-overlooked differences between men and women in cardiovascular disease. The initiative aims to inform doctors, women, and the wider public while supporting prevention and research in women’s heart health. FHchol Austria will contribute through social media activities and by visibly supporting the campaign, encouraging people to wear red or a red accessory on the first Friday of February.

FHchol Austria co-organises FH Festsymposium

FHchol Austria is co-organising the **FH Festsymposium** on **20 February 2026**, held in honour of Prof. Kurt Widhalm, President of its Scientific Board, on the occasion of his 80th birthday. The symposium will present practice-oriented insights into current developments in the diagnosis, treatment and prevention of familial hypercholesterolaemia and Lp(a). With expert speakers from Austria and abroad, the event targets physicians and other health professionals, strengthening awareness of the familial nature of FH and effective strategies for early detection and prevention.

China: FH China

Advancing research and patient engagement

FH China is advancing care and research for familial hypercholesterolaemia through the Homy Patient Registry, launched in August 2025 and now enrolling 77 patients with homozygous FH, with a report planned for May 2026. The registry will expand to additional rare lipid disorders in 2026, alongside research on diagnostic delay, outcomes and quality of life. In parallel, FH China is strengthening patient leadership through interviews and a structured Patient Ambassador Empowerment programme, while improving access to care via a national diagnosis and treatment map, a multidisciplinary expert network, and coordinated awareness and advocacy activities throughout 2026.

Czechia: ČAKO

New Lp(a) patient resources and care tools

ČAKO has published a new patient brochure on lipoprotein(a), adapted from FH Europe Foundation materials and reviewed by Czech experts to reflect the national healthcare system. A key update highlights the new preventive check-up system in the Czech Republic, in force since 1 January 2026, which introduces more frequent and individualised GP check-ups and includes routine Lp(a) testing. Early impact is already visible, with general practitioners reporting a 250% increase in Lp(a) testing within weeks.

Alongside this, ČAKO continues to develop **kardiomapa.cz**, a nationwide map of outpatient cardiologists designed to improve patient referrals and access to care. The project is being

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Netherlands: Stichting VrouwenHart

WrouvenHart 5-year anniversary

On Monday, 9 February 2026, Stichting VrouwenHart will celebrate its 5-year anniversary with a special meeting at Nieuwspoort in The Hague. The event will reflect on progress made and look ahead to the future of women's heart health, sharing the latest national and international developments. Leading experts, including **Prof. Hester den Ruijter, Prof. Jeanine Roeters van Lennep, and Sanne Peters**, will contribute scientific perspectives, alongside insights from women's lived experiences. The gathering reflects our belief that better care is built on listening, collaboration, and shared knowledge.

UK: Action FCS

Reminder: Action FCS Patient & Carer Event 27/28 February 2026

Action FCS will be hosting its first dedicated event for people living with FCS, parents of children with FCS, and their carers. The event will feature an engaging programme delivered by leading FCS experts. Attendees will have the opportunity to connect with others in the FCS community, with FCS-appropriate, and halal catering provided throughout. For those unable to participate in person, a virtual attendance option will be available. Further information is available here.

Global: Global Heart Hub

2025 Higlights

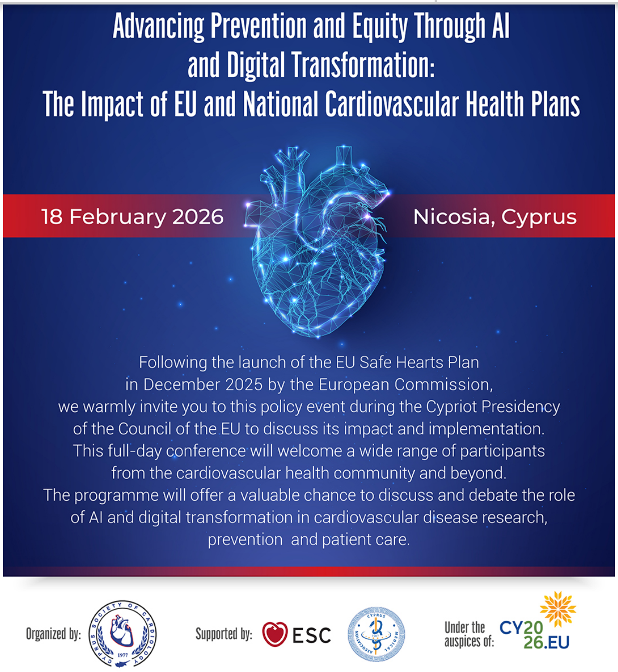
Global Heart Hub has released a 2025 highlights video showcasing key moments from 2025, including the Unite Annual Summit, in-person Network meetings, training sessions and more. As the new year begins, Global Heart Hub extends its sincere thanks to its community and the FH Europe Foundation. Their continued support, collaboration and commitment have helped drive meaningful progress for heart patients around the world.

PARTNER NEWS

Cyprus Society of Cardiology

Save the Date: EU Cardiovascular Policy Event in Cyprus

A high-level policy event will be held on **18 February 2026 in Nicosia, Cyprus**, under digital transformation can advance prevention and equity in cardiovascular health, while examining the impact and implementation of EU and national cardiovascular health plans. The event is organised by the Cyprus Society of Cardiology, with support from the European Society of Cardiology and the Cyprus Medical Association.



Advancing Prevention and Equity Through AI and Digital Transformation:
The Impact of EU and National Cardiovascular Health Plans

18 February 2026
Nicosia, Cyprus

Following the launch of the EU Safe Hearts Plan in December 2025 by the European Commission, we warmly invite you to this policy event during the Cypriot Presidency of the Council of the EU to discuss its impact and implementation. This full-day conference will welcome a wide range of participants from the cardiovascular health community and beyond. The programme will offer a valuable chance to discuss and debate the role of AI and digital transformation in cardiovascular disease research, prevention and patient care.

Organized by:
Supported by: ESC
Under the auspices of: CY2026.EU

European Alliance for Cardiovascular Health (EACH)

EACH Summit Report

The report from the EACH Cardiovascular Health Summit is now available, capturing the key discussions and outcomes from the landmark event held in Brussels on 10–11 December 2025. The Summit brought together policymakers, clinicians, patients, researchers, and industry leaders to explore policy, research, and patient-centred approaches to cardiovascular health and to support the implementation of the newly adopted EU Safe Hearts Plan. The full report provides a valuable record of the Summit's insights and commitments. Read it here

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BBMRI ERIC

Upcoming Webinar

The **BBMRI-ERIC webinar on "Strengthening Biobanks through Patient and Public Involvement"** will explore how engaging patients and the public can improve research relevance, trust, and co-creation in biobanking. Experts and patient representatives will share practical insights and best practices. Register now to join this interactive session and learn how to make meaningful involvement a standard part of biomedical research.

European Patients' Forum (EPF)

Webinar Highlighting Patient Role in HTA

The EPF hosted an open webinar, *"1 Year On: HTA in Practice*', reflecting on the first year of the EU HTA Regulation. The session reaffirmed the essential role of meaningful patient involvement participation and training needs. The discussion showcased EPF’s wider HTA work, including EU EDiHTA and the upcoming EPF Barometer launching in June 2026. **Watch the recording**.

NEWS FROM AROUND THE WORLD

Croatia

Know your number

The Croatian Hypertension League, featured the “Hunting the Silent Killer” campaign on *Good Morning Croatia*, highlighting early detection of hypertension, dyslipidaemia, and FH. With its message **“Know Your Number,”** the campaign is now reaching communities via a mobile screening unit. Young physicians emphasised the role of awareness and education. Aligning with the EU Safe Hearts Plan, the initiative shows how community action can empower citizens to manage cardiovascular risk and prevent disease.

Switzerland

CATCH Study

The **CATCH study**, a Swiss research initiative launched in 2020 (first results should be published in early 2026), focuses on identifying FH through family-based (cascade) screening, enabling earlier diagnosis and treatment for affected relatives. The study closely aligns with **PERFECTO’s shared goal** of strengthening early detection and paediatric screening for FH to prevent cardiovascular disease later in life. **Read the interview of Dr Nanchen here** (in French).

KNOWLEDGE HUB

Rare Disease at the WHO Executive Board Meeting

As the WHO Executive Board meets in Geneva in February, Rare Diseases International is urging countries to push for concrete next steps on the Global Action Plan on Rare Diseases, which has not yet been developed despite initial progress reported by the WHO. This session is a key moment for governments to call on the WHO to move forward with a clear, inclusive plan that reflects the needs of people living with a rare disease worldwide.
Read RDI’s Position paper here.

SAVE THE DATE

- **February: Heart month,** in the UK and USA

- **28 February: Rare Disease Day, EURORDIS**
- **24 March: Lp(a) Awareness Day, FH Europe Foundation**
- **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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