
Welcome to the August 2026 edition of Heart Beat News



Heart Beat News

31 August 2026

September is set to be a busy month for our community, with **FH Awareness Day, EU Screening Week and World Heart Day** creating important opportunities to champion earlier detection and prevention of cardiovascular diseases and inherited lipid disorders. In this edition, discover how our Network is taking action, alongside news from our research projects, Ambassadors and partners, and the latest developments in inherited lipid disorders and cardiovascular health.

FH EUROPE FOUNDATION NEWS

From awareness to action: our international FH community comes together

As **FH Awareness Day** approaches, our global community is turning awareness into action. During two FHEF community calls in August, members shared inspiring activities from across Europe, Asia, the Middle East and Africa, from public cholesterol screening and educational events to patient videos, policy workshops and advocacy for better

access to care. Set against growing momentum from the EU Safe Hearts Plan and the first EU Screening Week, the discussions showed the power of connecting local action, shared learning and patient voices to advance earlier FH detection and help prevent the preventable.



Get involved in the first-ever EU Screening Week

UPDATES: You can now **register your activities** on the Commission's portal and **be part of a wider campaign**. The first-ever EU Screening Week will take place from 28 September to 4 October 2026, shortly after FH Awareness Day and coinciding with World Heart Day.

FHEF encourages patient organisations, healthcare professionals, advocates and partners across the EU to **organise or promote screening, awareness or educational activities** and to **register them** on the **European Commission's platform by 20 September**. Existing programmes and activities taking place close to the official week may also be eligible, although FHEF is seeking confirmation from the Commission. This is an important opportunity to put FH, elevated Lp(a), FCS and other inherited lipid disorders firmly on Europe's prevention and early-detection map. [Read more about how to get involved.](#)

EU Screening Week letter

FH Europe Foundation convened leading scientific and advocacy organisations working in atherosclerotic cardiovascular disease to support the first EU Screening Week. In a joint letter to Commissioner Olivér Várhelyi's Cabinet, FHEF, EAS, the Lp(a) International Task Force and the EAS FH Studies Collaboration offered their collective expertise and networks to help translate the initiative—and the wider EU Safe Hearts Plan—into action across Member States. [Read the full letter and learn more.](#)

FH Europe Foundation at ESC Congress 2026

FH Europe Foundation was in Munich for the [European Society of Cardiology 2026 Congress](#), attending insightful sessions on **FH, cholesterol, triglycerides, Lp(a) and cardiovascular prevention**. The programme also featured contributions from our Trustee **Prof. Albert Wiegman**, as well as members of our **Scientific Advisory Committee** and the **Lp(a) International Task Force**. Stay tuned as we share insights from these discussions and other key highlights from this year's Congress, including the new **ESC guidelines on cardiac rehabilitation** and the **new definition of myocardial infarction**. More insights in the next Heart Beat edition.

AMBASSADOR NEWS



Summer travels, shared experiences

Who better to share travel tips than those who know what it's really like?

This summer, our Ambassadors shared their own tips for travelling while living with an inherited lipid disorder—practical advice shaped by real-life experience. A huge thank you to everyone who contributed and helped turn personal experience into useful guidance for the wider community.

Safe travels, wherever the rest of the summer takes you!

RESEARCH PROJECTS



New research sheds light on Lp(a) risk in Oman

A new study supported by PerMed FH provides important insights into lipoprotein(a) and cardiovascular risk in the Omani population. In 596 participants, researchers found higher Lp(a) levels among patients, particularly those with FH. Among people with FH, elevated Lp(a) was independently associated with a higher likelihood of cardiovascular disease. The findings highlight important population-specific differences in Lp(a) and support more personalised approaches to cardiovascular risk assessment and management.

[Read the article here](#)

NETWORK NEWS

FH awareness day – Local activities

We're excited to see **FH Awareness Day coming to life across our network**, with members organising activities in their own countries and communities. It's inspiring to see so many local initiatives helping to put FH in the spotlight and amplify our shared call for greater awareness and earlier detection.

Austria – FHchol

On **FH Awareness Day**, [FHchol Austria](#) and Meine Herzklappe will host a **Heart Health Day at Vienna's Donauzentrum**, offering free testing for cholesterol, triglycerides, Lp(a), blood glucose and blood pressure, with expert counselling on site. Visitors can also access heart valve checks and learn how to use a defibrillator. Several Austrian heart organisations will join the event to provide information, with media coverage supported by the German platform **Gut zum Herz**. [Read more](#)

Czech Republic – ČAKO

The **11th annual FH Week and World Heart Day**, organised by [ČAKO](#) with support from the Czech Society for Atherosclerosis, will take place across the Czech Republic throughout September and October. At least **eight stops** are planned, aiming to screen and educate more than **900 people** through cholesterol, blood pressure and blood glucose testing, alongside individual advice on cardiovascular prevention and referral for those at risk. Since the

initiative began in 2015, **9,400 people have been screened and educated, and 54 families with FH identified.** [More information from ČAKO](#)

Greece – LDL Greece

[LDL Greece](#) will co-host a **community cholesterol screening event on 18 September** with the Municipality of Kalamaria to raise awareness of FH and the importance of early detection. Visitors will be able to have their cholesterol levels checked, meet patient association representatives, hear lived experiences, and ask questions about FH. People found to have high LDL-C levels will receive further information about the possibility of FH and be encouraged to seek appropriate medical assessment. The event will be held under the auspices of **Rare Diseases Greece and FH Europe Foundation.**

Netherlands – LEEFH



WEBINAR – 1 OKTOBER 2026 – 19:00 – 20:30, met

				
Jeanine Roeters van Lennep	Albert Wiegman	Willemijn Corpeleijn	Kees Hovingh	Dennis Boor

Ondersteund door:



On 1 October, [LEEFH](#) will be hosting a webinar discussing two important European consensus papers published in 2026: **familial hypercholesterolaemia in children and adolescents**, and the **organisation and funding of lipid clinics**. Prof. Roeters van Lennep, Prof. Wiegman and Dr. Corpeleijn will explore the key recommendations and answer questions from participants. Dennis Boor will also provide an update on the LEEFH Foundation. [More information here](#)

Singapore – FHCARE Singapore

FHCARE Singapore is preparing **several activities ahead of FH Awareness Day** on 24 September. An **outreach booth** on 3 September will raise public awareness of FH and provide information about FH genetic testing, supported by **educational posters** displayed from 3–9 September. On 5 September, a **patient engagement event** will explore the importance of genetic testing, treatment options and FH research. The event will also include a roundtable discussion

where participants can share their FH journeys, identify unmet needs, and explore opportunities to strengthen support and collaboration.

China: Homy FH China Patient Network

Supporting the recruitment for Two Paediatric Clinical Trials in China

In August, [**Homy FH China Patient Network**](#) supported the dissemination of **two paediatric clinical trials for HeFH and HoFH** in China. Leveraging its FH patient registry, the organisation identified potentially eligible patients and proactively informed them about opportunities to contact trial sites for further screening. Through these efforts, Homy FH continues to bridge the gap between clinical research and the FH community in China, helping facilitate access to investigational therapies and supporting the development of new paediatric treatment options.

Conducting Rapid Patient Needs Assessment on Lomitapide Access to Inform Reimbursement Advocacy

Following the availability of **lomitapide in China**, Homy FH China Patient Network has been engaging directly with **HoFH patients via WeChat** to better understand their needs and barriers to accessing this new therapy. Discussions are exploring willingness to access treatment, insurance coverage and financial constraints. These insights will inform a **Joint Action Statement** to be released at a September advocacy workshop, supporting evidence-based policy efforts to improve access to innovative HoFH therapies in China.

Hosting HoFH Patient Report Launch & Advocacy Workshop in Beijing

Following the release of its **2026 Brief Report on the Clinical Management & Economic Burden of Chinese HoFH Patients**, Homy FH China Patient Network will launch the full report in **Beijing on 18 September**, drawing on data from 122 patients and an economic burden survey of 112 families. This will be followed on 19 September by an advocacy workshop bringing together HoFH and FCS patients and families to develop joint action statements and practical strategies to advance **drug reimbursement and policy change**.

Iraq: FH Iraq

"Check Lipids, Protect Your Life" Campaign

FH Iraq recently launched its “**Check Lipids, Protect Your Life**” community awareness campaign, highlighting the importance of knowing your lipid levels for cardiovascular disease prevention and early detection. In collaboration with Moon Polyclinic, the initiative provided **lipid profile screening to 750 people**, helping participants better understand their cardiovascular risk while also supporting the identification of people who may be living with undiagnosed genetic lipid disorders, including FH.



Netherlands: Stichting VrouwenHart

Strengthening women’s cardiovascular health

On 23 August, [Stichting VrouwenHart](#) brought its volunteer team together from across the Netherlands to reflect on its mission and plan for the future. The organisation continues to combine peer support, patient advocacy, research and awareness-raising to improve recognition and care of cardiovascular disease in women. Its work includes contributing the patient perspective to research projects such as EXIT-CVD and Proactive, alongside running six peer-support groups where women can connect and share their experiences. [Read more](#)



PARTNER NEWS

World Heart Federation (WHF)

World Heart Day 2026: Don’t Miss a Beat

The [World Heart Federation \(WHF\)](#), has launched its World Heart Day 2026 campaign, once again calling on the world

to Don't Miss a Beat. Ahead of **29 September**, the campaign highlights the **importance of recognising cardiovascular warning signs**, accessing timely care, and addressing preventable risk factors. Building on last year's global momentum, WHF is inviting individuals and organisations worldwide to help ensure that fewer people miss opportunities for earlier detection, prevention and better heart health.



[Learn more](#)

European Patients' Forum (EPF)

Upcoming opportunities from EPF

The European Patients' Forum (EPF) has two opportunities coming up this autumn. On 15 September, an open webinar will explore findings from the **EPF Barometer**, with a focus on strengthening meaningful patient involvement in Health Technology Assessment (HTA). **[Register for the webinar](#)**.

EPF is also preparing its **Youth Congress 2026**, taking place in Brussels on 23–24 October, bringing together young patient advocates and health stakeholders to strengthen youth engagement in health policy. **[Learn more about the Youth Congress](#)** and access the endorsement form.

EURORDIS

Webinar on the European Blueprint for Rare Diseases

Join the **EURORDIS** webinar on the European Blueprint for Rare Diseases on **18 September** and help shape the future of rare disease policy in Europe. The Blueprint aims to inform a future **EU Action Plan on Rare Diseases**, addressing priorities including earlier diagnosis, access to specialised care and treatments, research and innovation, integrated care and better use of health data. The webinar is an opportunity to hear the latest proposals and contribute to ensuring that the experiences and needs of people living with rare conditions are reflected in future policies.

18 September 2026 | 14:30–16:00 CET

[Register for the webinar](#)

World Orphan Drug Congress (WODC)

WODC 2026

FH Europe Foundation will be attending the [**World Orphan Drug Congress \(WODC\) Europe 2026**](#) on **October 27-28**, where we will have a booth and look forward to connecting with the rare disease community.

FHEF Ambassadors and Network Members can benefit from a limited number of complimentary passes, while a special **discounted registration rate is available** to our wider community. The Congress will bring together patient organisations, researchers, healthcare professionals, policymakers and industry to discuss the latest developments across rare diseases.

Interested in attending? **Contact elsie@fheurope.org for details on complimentary passes and the FHEF discount code.**

KNOWLEDGE HUB

New research on evinacumab in children with HoFH

A new study published in the **Journal of the American Heart Association** explored the benefits of evinacumab in 13 children with **HoFH**. After a median follow-up of two years, **69% reached the recommended LDL-C goal**, compared with none before treatment. Treatment was also associated with less frequent lipoprotein apheresis and, in most children, stabilisation, regression or absence of coronary plaque progression, highlighting the potential to improve LDL-C control while reducing treatment burden.

[**Read the full article here**](#)

OECD calls for stronger cardiovascular health checks across Europe

A new [**OECD**](#) policy brief highlights the need to strengthen cardiovascular health checks across the EU, supporting the ambitions of the EU Safe Hearts Plan on earlier detection and prevention. Importantly, gaps in cholesterol testing remain: **16% of adults aged 25–64 had not had their cholesterol checked in the previous five years**. The OECD highlights routine lipid testing, alongside blood pressure and glucose checks, as a simple approach to improve early detection of cardiovascular risk factors, and advocates a life-course approach starting in childhood to identify inherited and emerging risks early. [**Read the full document**](#)

Patient Safety Day

On **17 September**, **World Patient Safety Day 2026** will focus on “**Safe care for noncommunicable diseases**”, highlighting the importance of safer, coordinated and patient-centred care for people living with NCDs throughout their care journey.

Ahead of the day, the **World Patients Alliance** is hosting the global webinar “**Safe Care for Life: A Global Call to Action for Safer NCD Care**” on **16 September 2026 at 08:00 ET (14:00 CEST)**. The webinar will bring together patients, healthcare professionals, policymakers and other stakeholders to explore patient safety risks, meaningful patient engagement and practical actions to prevent avoidable harm. [Register for the webinar](#)

SAVE THE DATE

- **15 September: Apheresis Awareness Day**
- **17 September: [World Patient Safety Day](#)**, World Health Organisation (WHO)
- **24 September: [FH Awareness Day](#)**
- **28 September-6 October: [EU Screening Week](#)**
- **29 September: [World Heart Day](#)**, World Heart Federation
- **27-28 October: [World Orphan Drug Congress](#)**, Amsterdam, The Netherlands
- **6 November: [FCS Awareness Day](#)**
- **6-8 November: [FHEF](#) Annual Network Meeting**, Dublin, Ireland

