

Heart Beat News

6 September 2026

What a month for our community! This edition comes exceptionally just after EU Screening Week, following weeks of strong momentum around earlier detection and prevention—from FH Awareness Day and screening initiatives to the European Commission's new proposal for a Council Recommendation on cardiovascular health checks. We also bring you new research, treatment updates and opportunities to learn, connect and get involved.

FH EUROPE FOUNDATION NEWS

A Step Forward for Cardiovascular Screening in Europe

On September 28th, the European Commissioner for Health, Olivier Varhelyi announced the [Proposal for a Council Recommendation on cardiovascular health checks](#), marking an important step for prevention, early detection and screening in Europe. FHEF welcomes the recognition of FH, Lp(a), triglycerides, family history and inherited cardiovascular risk. We will now work with our community to protect this progress and strengthen the life-course approach, ensuring early detection for inherited lipid disorders truly starts early in life.

[Read more here](#) and join our community call to unpack the topic.

□ Thursday, 8 October | 18:00 CEST ([Register here](#))



From FH Awareness Day to EU Screening Week

This year's [FH Awareness Day](#) saw incredible engagement across our community, both online and through activities on the ground, with our campaign toolkit widely used and adapted across countries. The momentum was further amplified by a dedicated [European Commission Public Health page](#) and carried into [EU Screening Week](#), reinforcing the importance of knowing your numbers and detecting cardiovascular risk early. Our webinar trilogy with [EPHA](#) is also continuing: the first webinar is now available to watch on YouTube ([watch here](#)), and registration remains open for the **next sessions**, exploring what cholesterol test results mean and treatment today and tomorrow:

□ 13 October | 18:00 CET ([Register here](#))

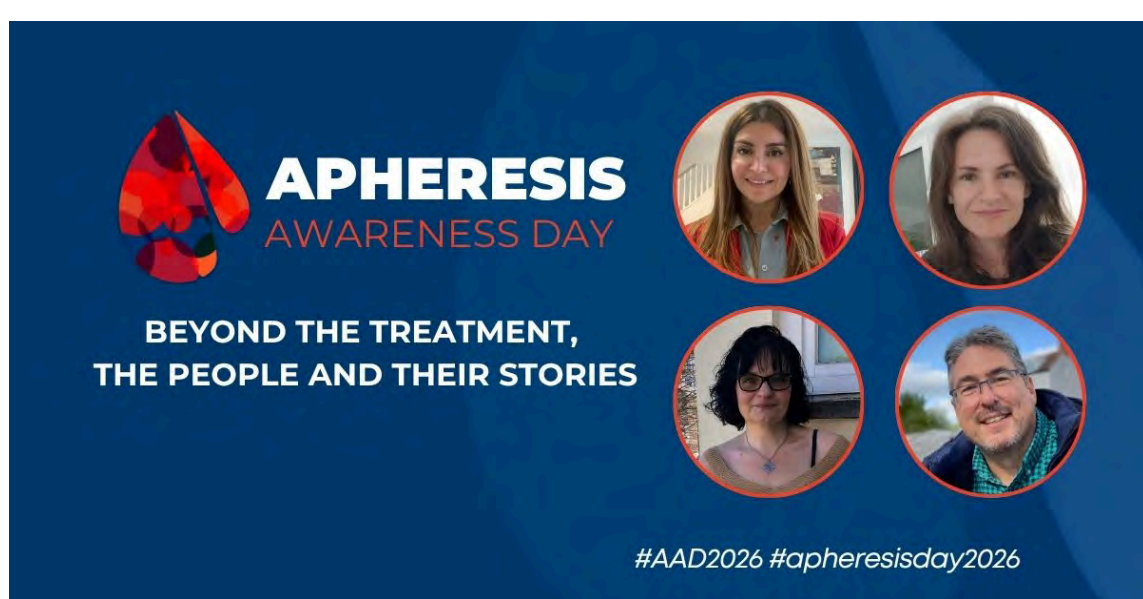
□ 27 October | 18:00 CET ([Register here](#))

AMBASSADOR NEWS



Together for FH Awareness Day

[FH Awareness Day 2026](#) once again showed the incredible commitment of our community. **A huge thank you to all our Ambassadors** who helped raise awareness, share key messages and bring FH into conversations across countries and communities. A very special thank you to those who shared their personal diagnosis stories. By speaking openly about their experiences, they put a human face on FH and showed why earlier detection and diagnosis matter.



Apheresis Day: from Facts to Real-Life Experience

For Apheresis Awareness Day, we put the spotlight on the **people behind the treatment**. Through our blog, members of our community shared their personal experiences of living with a condition requiring apheresis—from the realities of **regular treatment to its impact on everyday life**. A **huge thank you** to everyone who shared their story and helped raise awareness through lived experience. [Discover their stories on our blog](#).

RESEARCH PROJECTS



perfecto
Preventing the Preventable



PERFECTO and FH-EARLY Presentations at the Geneva Health Forum

Data and insights from [PERFECTO](#) and [FH-EARLY](#) will be presented at the [Geneva Health Forum 2026](#), taking place on **10–12 November** at Campus Biotech in Geneva. Posters from both projects have been accepted, providing an opportunity to showcase their work on **paediatric FH screening, earlier detection and improved approaches to FH care** to an international global health audience.

NETWORK NEWS

Austria: FHchol Austria

Bringing Screening into the Community

For FH Awareness Day, [FHchol Austria](#) brought heart health directly to the community in Vienna, testing **200 people for Lp(a)** and **100 for lipid profiles and long-term blood glucose**, alongside blood pressure and heart valve checks. Expert counselling helped participants understand their results and encouraged follow-up where elevated cardiovascular risk factors were identified.

China: Homy FH China Patient Network

Launch of China's First HoFH Patient Survival Report and HoFH/FCS Patient Advocacy Workshop



On 18 September, [Homy FH China Patient Network](#) and partners launched the **2026 China HoFH Patient Survival Survey Report**, the country's first systematic report on HoFH survival. Based on data from **122 people with HoFH**, it highlights major gaps in early diagnosis, LDL-C control and access to care, as well as the substantial financial burden on families. The report sets out six policy recommendations to help improve HoFH detection, treatment and access in China. [Read more](#)



And on 19 September, Homy FH China Patient Network brought together people living with **HoFH and FCS** and their families for a **patient advocacy workshop in Beijing**. Through training and group discussions, participants identified shared priorities and developed action plans for improving access and reimbursement, helping build a stronger community of patient advocates in China. [Read more](#)

Czech Republic: ČAKO

[ČAKO](#) marked FH Awareness Day with its 11th annual FH Week in Czechia, this year also joining EU Screening Week and the Know Your Numbers campaign. Around 400 people have already received cholesterol screening and medical consultations, identifying four possible cases of FH, with activities continuing through October. On World Heart Day, a major screening event in Prague received prime-time TV coverage, while the city's Franz Kafka bust was illuminated in red to raise awareness.



Greece: LDL Greece

FH Awareness Day in Greece: Bringing Cholesterol Screening to the Community

As part of **FH Awareness Day**, [LDL Greece](#) and the Municipality of Kalamaria organised a community screening event on **18 September**, offering free cholesterol checks alongside information about FH and patient experiences. **More than 100 people were tested**, with strong public participation throughout the event. For some participants, the screening identified cholesterol levels requiring further attention, providing an important opportunity to encourage follow-up with their healthcare professionals and reinforcing the value of **knowing your cholesterol numbers**.

Italy: AISC

Community Prevention and Cardiovascular Policy in Italy

From **19–30 September**, [AISC](#) APS took its mobile outpatient clinic across Italy, offering information on cardiovascular health, preliminary screening and free assessment of key risk factors. The initiative aimed to promote **earlier detection and prevention** while strengthening connections between citizens, patient organisations and local healthcare services.

On **World Heart Day**, AISC APS also participated in the **States General on Cardiovascular Health** in Rome. Maria Rosaria Di Somma brought the patient perspective to discussions on **prevention, screening, timely diagnosis, access to care and quality of life**, alongside wider discussions on the European **Safe Hearts Plan**.



Italy: ANIF

Italy Launches 10-Point Manifesto for HoFH

A new Italian **Manifesto on HoFH** sets out 10 actions to improve diagnosis and care, including **earlier diagnosis, paediatric screening, timely treatment and more equitable access across regions**. Promoted by OMaR with contributions from clinical experts and patient organisations [ANIF](#), [GIP-FH](#) and [AIDE](#), the initiative also calls for stronger collaboration across healthcare disciplines to improve the care pathway for people living with HoFH. [Read the article and discover the Manifesto](#).

Iraq: FH Iraq

Raising Awareness Through Local Media

[FH Iraq](#) recently took part in a **Kurdish-language television interview** to discuss dyslipidaemia, address common misconceptions and highlight the importance of early detection and cardiovascular disease prevention. The interview forms part of the organisation's ongoing efforts to use trusted local media to increase awareness of lipid disorders across the Kurdistan Region of Iraq.

Netherlands: LEEFH

Insights from the Dutch Program on FH Cascade Testing

New research published in the **Journal of Clinical Lipidology** provides insights from a decade of the Dutch FH cascade screening programme (2014–24), conducted by [LEEFH](#). The study describes its **network-based approach** and examines diagnostic yield, identification of relatives, referral patterns and geographic coverage, offering valuable lessons for strengthening FH detection through cascade screening. [Read the study](#)

Netherlands: Stichting VrouwenHart

Joining EXIT-CVD Consortium Kick-off in Groningen

On 17–18 September, the **IHI EXIT-CVD** consortium met in Groningen for its in-person kick-off, bringing partners together to align on the project's objectives and next steps. As a project partner, [Stichting VrouwenHart](#) contributed the patient perspective, working alongside researchers, clinicians and other partners to help ensure lived experience informs this major European cardiovascular research initiative. [Read more](#)

Supporting “Know Your Numbers” campaign

On **World Heart Day (29 September)**, Stichting VrouwenHart joined the **#KenJeGetallen (Know Your Numbers)** campaign in Amsterdam and Haarlem, offering free blood pressure, cholesterol and blood sugar checks. Taking place during **EU Screening Week**, the initiative combined early detection with greater awareness of **women’s cardiovascular health**, helping people better understand their risk factors and encouraging prevention within the community.



Switzerland: Familles en Coeur

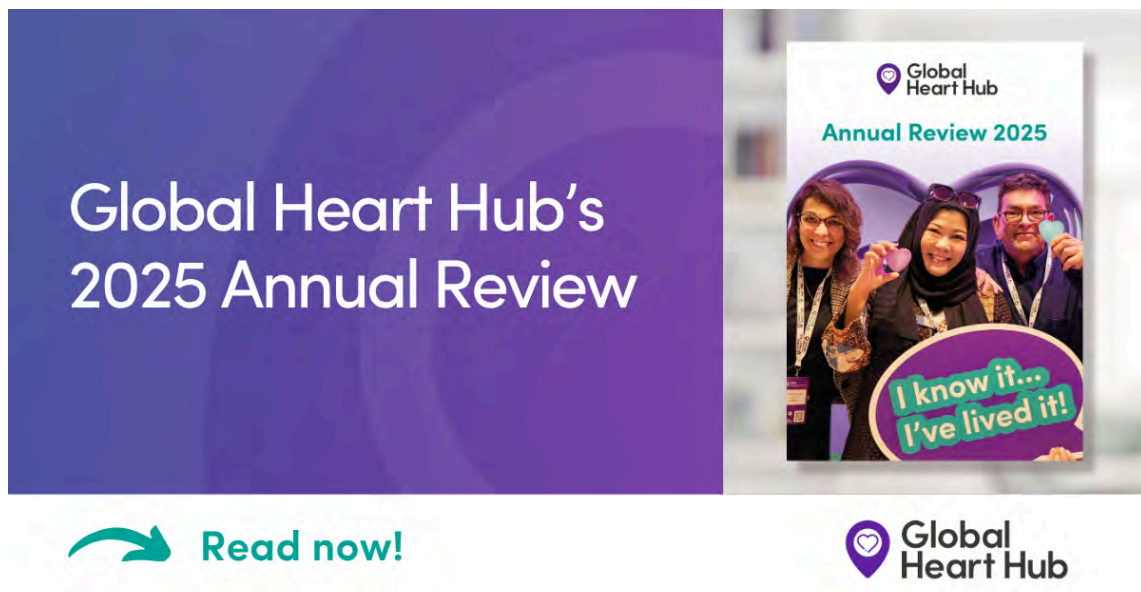
Welcome to our Network, Familles en Coeur!

Launched on **World Heart Day**, **Familles en Cœur** is a new Swiss organisation supporting people and families affected by inherited lipid disorders. With a focus on **Suisse romande**, it aims to reach both French-speaking communities and English-speaking expats, improving access to information and promoting awareness, prevention and family screening.

Global: Global Heart Hub

Looking Back at 2025

Our partner **Global Heart Hub (GHH)** has published their 2025 Annual Review, highlighting a year of progress in strengthening the voice of people affected by cardiovascular disease worldwide. Throughout 2025, GHH grew its network to **154 patient organisations across 44 countries**, advanced patient-led research, launched its Clinical Research Initiative, strengthened action on women’s cardiovascular health, and contributed to the development of the first-ever EU Cardiovascular Health Plan. FH Europe Foundation is pleased to be part of this global community, working together to ensure that the voices and lived experiences of people affected by cardiovascular disease help shape research, policy and action. [Read GHH 2025 Annual Review](#) and discover the highlights and impact of the year



PARTNERS NEWS

EURORDIS

Open Academy Schools 2027

EURORDIS Open Academy Schools 2027 applications are now open. Continue your learning journey in the wider rare disease community through specialised training and networking opportunities. The schools will take place **7-10 June 2027** in **Castelldefels, Barcelona, Spain**. Applications close **16 October 2026**. Link for applications: <https://openacademy.eurordis.org/open-academy-schools/>

Please let us know if you are accepted so we can update our records, or if you have already completed a **EURORDIS Open Academy** or **EUPATI** training programme.

European Patients´ Forum (EPF)

EPF Youth Congress 2026: A New Platform for Young Patient Voices

The first **EPF Youth Congress** will take place in **Brussels on 23–24 October**, bringing together young patient advocates and health stakeholders from across Europe to explore how young people living with chronic conditions can help shape health policy and more inclusive health systems.

Are you a member of the EPF Youth Group or planning to attend the Congress? We would love to hear from you! Get in touch with Elsie (elsie@fheurope.org) so we can share your involvement and highlight the voices and contributions of young advocates across our community. [Learn more about the Congress.](#)



EUPATI

Annual General Meeting: From Patient Voice to Patient Evidence

At the **EUPATI Annual General Meeting 2026** in Brussels, discussions focused on how **Patient Experience Data** can meaningfully inform research, medicines development and healthcare decisions. FHEF was represented by Elsie Evans, EUPATI Fellow and FHEF Ambassador. Key messages included involving patients from the start, generating robust and structured evidence, strengthening education for both patients and researchers, and ensuring communities see the impact of their involvement.

Are you an EUPATI Fellow?

Connect with us at elsie@fheurope.org so we can build on this expertise together. [Read more about the insights from the Meeting.](#)

NEWS FROM AROUND THE WORLD

New LDL-C-Lowering Option Approved in Europe

The **European Commission** has approved a new oral LDL-C lowering **therapy**, both as monotherapy and in combination with ezetimibe, for adults with **primary hypercholesterolaemia, including HeFH, or mixed dyslipidaemia**. The approval adds another treatment option for people who need additional support to reach recommended LDL-C levels.

KNOWLEDGE HUB

EPF Recommendations on the EU Biotech Act

The **European Patients´ Forum (EPF)** has published [recommendations on the EU Biotech Act](#), calling for patient needs, public health and equitable access to remain central as negotiations progress. EPF highlights priorities including **meaningful patient involvement**, access to innovation, transparency, and strong standards for clinical trials and patient safety. These issues are particularly relevant for people living with rare and inherited conditions, where scientific advances only make a difference when they translate into accessible treatments and better care. [Learn more](#)

Webinar: European Health Data Space State of Play

The [European Health Data Space \(EHDS\)](#) aims to make health data easier and safer to access and share across Europe. This webinar will provide an **update on the new rules**, their implementation, and how better use of health data can support healthcare, research and patient outcomes.

📅 9 October | 09:30–11:00 CEST [Register here](#)

Webinar: Connecting Civil Society Organisations to Advocate for the EU Budget

This webinar will unpack the upcoming **EU budget discussions**, provide practical **advocacy tools**, and help patient and civil society organisations work together to ensure their voices are reflected in future funding decisions for health, research and civil society.

📅 20 October | 10:00–12:00 CET [Register here](#)

Patient Expert Training Programme: Further Learning with EUPATI

The [EUPATI](#) Patient Expert Training Programme helps **patient advocates** complement their lived experience with knowledge of how medicines are researched, developed, assessed and approved. Through **online learning, webinars and interactive training**, participants build the skills to contribute confidently to research, clinical trials and healthcare decision-making. The 2026–2027 programme runs for **12–14 months**, with **registration closing on 1 November 2026** or earlier if places are filled. Interested Ambassadors and community members are encouraged to apply and let us know if accepted so we can support their journey. [Learn more about the programme](#)

Podcast: From FH and Lp(a) to Better CVD Prevention

A new [EMJ podcast](#) series, **Modern Lipidology in CVD Prevention**, explores key developments shaping cardiovascular prevention. Featuring lipidologist Devaki Nair, the series covers **FH, Lp(a), and community-based screening**, including how to improve detection and reach diverse populations to reduce cardiovascular risk. [Listen to the series](#)

Report: How Does the Public View Personalised Medicine?

A new [EP PerMed](#) report explores public awareness and perceptions of personalised medicine, highlighting its perceived benefits alongside the need for greater awareness, trust and equitable access as personalised approaches develop across Europe. [Read more](#)

Findings from the EPF Barometer 2026

The [EPF Barometer 2026](#) reveals significant differences in how patients and patient organisations are involved in health policy across Europe. Key challenges include **limited resources, a lack of formal frameworks and transparency, and involvement that often comes too late in decision-making**. The findings reinforce the need to strengthen patient organisations and equip advocates with the skills and opportunities to bring lived experience meaningfully into health policy. [Watch here](#).

Lp(a)HORIZON: Lp(a) Internation Task Force Statement

Following the topline results from the Lp(a)HORIZON trial, the [Lp\(a\) International Task Force \(ITF\)](#) is calling for caution until the full data are available. While the trial did not meet its primary cardiovascular endpoint, elevated Lp(a) remains an important inherited risk factor, and testing, early detection and cardiovascular prevention remain essential. Read the full [Lp\(a\) ITF statement](#)

SAVE THE DATE

- **27-28 October:** [World Orphan Drug Congress](#), Amsterdam, The Netherlands
- **6 November:** [FCS Awareness Day](#)
- **6-8 November:** [FHEF](#) Annual Network Meeting, Dublin, Ireland

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