Welcome to the September edition of Heart Beat News

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FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

3 October 2025

September has been a truly remarkable month for our community. With **FH Awareness Day**, we witnessed incredible engagement, solidarity, and passion from the community in Europe and across the globe. This collective energy was further amplified at our successful event at the **European Parliament**, where our Ambassadors delivered deeply inspiring and emotional speeches that resonated with all in attendance. Their voices, coupled with the strong commitment from Members of the European Parliament Romana Jerkovič and Tomislav Sokol—who reiterated their support for making the management of inherited lipid disorders a cornerstone of cardiovascular health in the EU—have left our team more energised than ever. Together, we are building unstoppable momentum for change.

FH EUROPE FOUNDATION NEWS

A Decade of Patient-Led Advocacy Comes Full Circle at the European Parliament

On 25 September, FH Europe Foundation returned to the European Parliament to mark ten years of patient-led advocacy. What began as a call for recognition of inherited lipid disorders has grown into a driving force in European health policy. The event, *“Cardiovascular Prevention as the Cornerstone of a Competitive Europe”*, co-hosted by **MEP Romana Jerkovič and MEP Tomislav Sokol**, highlighted both progress and urgency: prevention is an investment, not a cost, and patient stories remain the most powerful call to action. With the launch of the Brussels International Declaration on Lp(a) Testing and Management earlier this year, the next decade is set to turn policy commitments into real-world change — so fewer lives are lost to preventable heart disease. **Read more**.

Meeting with EU Health Commissioner Olivér Várhelyi

On 18 September, in Brussels, FH Europe Foundation met EU Commissioner Olivér Várhelyi to exchange views on the forthcoming EU Cardiovascular Health Plan. The discussion stressed the urgency of addressing inherited conditions that remain largely undiagnosed across Europe. FH Europe Foundation highlighted the need for systematic screening, innovation, and equitable access to care, and reaffirmed its readiness to work with the EU to #PreventThePreventable. **Read more**.

EC CVH plan consultancy - FHEF response

The European Cardiovascular Health (CVH) Plan marks an important step toward strengthening cardiovascular health across the region. It outlines priorities for prevention, care, and research, with the goal of reducing the burden of heart disease and stroke. After consulting the community, FH Europe Foundation has developed a response, stressing the importance of ensuring that inherited lipid disorders are fully recognised within the plan's priorities. This focus is vital to prevention and care efforts. You can read FHEF's full response, now **on our website**.

FH Awareness Day 2025 - A Global Success

FH Awareness Day 2025 was a resounding success, with activities and advocacy taking place across our network and beyond. From Ambassadors sharing their lived experiences at international events, to members hosting local awareness activities, to individuals and organisations using our toolkit and spreading the message on social media – the collective effort truly amplified the call for better FH detection and care.

This year showed the power of collaboration: Ambassadors worked side by side with clinicians and policymakers, network members raised awareness in their communities, and countless individuals helped spread the word online. Together, we made FH visible, reminding decision-makers and the public why prevention and early diagnosis matter.

A big thank you to everyone who took part in this important global effort—you are the driving force behind change!

Read more about the highlights and inspiring activities on our **news blog**.

Join FHEF at the World Orphan Drug Congress Europe

We are delighted to announce that the FH Europe Foundation will be present at the World Orphan Drug Congress Europe (WODC) in Amsterdam, **27-29 October 2025**, which brings together over 2,000 rare disease experts and more than 250 speakers on innovation, advocacy and policy.

We will have **a booth**, providing space to connect, share resources and raise awareness—spotlighting HoFH, FCS and our wider community. **A limited number of free registrations** are available and we would warmly welcome members of our community to join us. Please email **elsie@fheurope.org** or send a WhatsApp message **by 15 October** to secure your place.

2025 Global Forum – Driving Person-Centred, Value-Based Care

We're **excited to support the 2025 Global Forum** and proud to see our Ambassadors, **Mădălina Iamandei (FH)** and **Helga Davidson (FCS)**, featured as speakers at this landmark event. Taking place on **4-5 December 2025** at the **Scottish Event Campus (SEC) in Glasgow** – and online – the Forum will tackle one of the most pressing issues of our time: *Creating Health Through Understanding and Personalising Value*. The event will address today's health care crisis by rethinking value—shifting towards person-centred, personalised care and prioritising prevention. It uniquely brings together leaders, policymakers, clinicians, and innovators to **drive partnerships, showcase AI and digital solutions, and supercharge prevention**.

Join us in **Glasgow or online** to explore practical tools, inspiring keynotes, and global collaborations shaping the future of **value-based health care**. Earn **12 CPD points**, connect with global leaders, and be part of vital conversations shaping the future of **person-centred, value-based health care**.

👉 Register today – **only nine weeks left**

Preparations for the Annual Network Meeting 2025

From **14 to 16 November**, the FH Europe Foundation Annual Network Meeting will take place in **Zagreb, Croatia**, bringing together leaders, Ambassadors, clinicians, researchers and partners for three days of collaboration, learning and community building.

The **Programme Committee** is working intensively to shape an inspiring agenda that blends science, policy, innovation and lived experience. Curious who they are? Meet the team and check the latest agenda on the event website.

*Please note: The meeting is **by invitation only**. Invitations will be sent out in the coming days, along with further programme updates. Stay tuned!*

AMBASSADOR PROGRAMME NEWS

Ambassadors actively driving change on FH Awareness Day

FH Europe Foundation Ambassadors played a central role in marking **FH Awareness Day 2025**. Across social media, ambassadors used the FH Awareness Day photo frame, key messages in multiple languages and resources from the FHEF toolkit to spread awareness far and wide. Their creativity and commitment ensured that the campaign reached diverse communities and encouraged conversations about familial hypercholesterolaemia.

In addition, Ambassador **Marwa Sadik** joined the IAS/EAS joint webinar, courageously sharing her lived experience and highlighting the importance of early detection and treatment. Meanwhile, in the UAE, FHEF co-hosted an **IAS-endorsed session** with **Dr Sarah Qureshi** and **M42 Academic Affairs**, featuring contributions from **Professor Albert Wiegman**, **Magdalena Daccord**, and patient Ambassador **Chyrel Lichaa**. This session successfully combined clinical expertise with patient voices, underlining the need for stronger global collaboration in FH care.

Michelle Watts and Scott Reavis to speak at CVCT Forum 2025, Washington DC

Two of our Ambassadors, **Michelle Watts** and **Scott Reavis**, have been selected as speakers at the **CVCT Forum 2025**, taking place this December at the Mayflower Hotel in Washington DC. The CVCT Forum is one of the most prestigious international platforms for cardiovascular clinical trialists, healthcare leaders and patient advocates.

Michelle and Scott will bring the patient perspective to centre stage, sharing their experiences and insights on how to make clinical trials more inclusive, impactful and patient-centred. By joining an international faculty of experts, they will ensure the voices of people living with inherited lipid conditions help shape the future of cardiovascular research, innovation and care.

Young Ambassadors gave voice to the Next Generation at EU Health Meeting

FHEF’s Young Ambassadors—**Athanasios Pallidis, Joanna Kacprzak, Aija Grizāne and Aeden Kaal**—met with the **EU Health and Food Safety Directorate** to share their experiences of living with inherited lipid disorders. Representing young people with HeFH, HoFH, elevated Lp(a) and FCS, they voiced the needs and hopes of millions across Europe.

With an estimated **90 million EU citizens** affected by these conditions, but diagnosis rates still low, their testimonies highlighted the urgent need for early detection and better care. As **Antonio Parenti, Director for Public Health, Cancer and Health Security at DG SANTE**, emphasised: *“Young people are the future, and their voices matter. That’s why it was essential to include them in shaping the EU Cardiovascular Health Plan, ensuring it reflects their priorities and ideas.”* Their participation shows the power of youth advocacy in shaping EU health strategies.

Lp(a) Ambassador to Speak at EACH Summit in Brussels

Marc Rijken, one of FHEF’s inspiring Ambassadors, has been selected as a panellist for the upcoming **EACH Summit** **in Brussels (10–11 December 2025)**. Marc’s personal story is a powerful reminder of why early detection matters: after surviving two heart attacks, he was diagnosed with elevated Lp(a), a genetic lipid disorder also affecting two of his daughters.

Marc has transformed his lived experience into tireless advocacy. As an active member of the **Lp(a) International Task Force**, he works to raise awareness of inherited cardiovascular risks and push for better policies around detection and care. His participation in the EACH Summit will ensure the patient perspective is central to the conversation on national cardiovascular strategies.

Read more about Marc’s journey and advocacy on our website: *My Story of Living With Elevated Lp(a)*.

RESEARCH PROJECTS

PerMed FH

Launch of the PerMed FH official website

The new PerMedFH project website is now live: **www.permedfh.eu**. It brings together the latest knowledge on personalised prevention and on genetic variants in familial hypercholesterolaemia (FH). The platform aims to support research, improve understanding, and contribute to better care and prevention of cardiovascular disease. Visit the website to learn more and get to know the dedicated team behind the project.

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perfecto
Preventing the Preventable

PERFECTO in Bulgaria: Empowering Youth on FH Awareness Day and World Heart Day

As part of the PERFECTO FH consortium, the Bulgarian Patient Forum launched a **creative awareness campaign** in Sofia to mark FH Awareness Day and World Heart Day. The initiative aimed to raise awareness of heart attack risks and engage both patients and the wider public. High school students participated in an educational lecture and shared their reflections through art, writing, and video. Their work was later presented in a **photo exhibition** (19 September - 3 October) in front of the National Palace of Culture.
The campaign's reach was amplified through **a live episode of the podcast *For Health*** with Assoc. Prof. Svetlin Tsonev and **a radio interview**, attracting over 4,000 viewers, and through national media coverage on **bTV**, featuring the Federation's Chairman Ivan Dimitrov alongside student Martin Bonev.

PERFECTO FH Project at the European Parliament

At the high-level event *"Cardiovascular disease prevention as a cornerstone for a competitive Europe"* in the European Parliament, Dr. Marius Geantă (INOMED) presented the **PERFECTO FH Project,** highlighting its goal to accelerate paediatric FH screening across Europe. He also shared insights from the Living Lab in Lerești, where medical, genomic, behavioural, and social data are integrated. *"PERFECTO is about understanding, implementation, equity, synergies and commitment,"* he said. **Read more**.

FH EARLY

FH EARLY gains international recognition

FH EARLY project has been making an impact across Europe and the US in recent months. The work was showcased on the **biggest cinema screen in Europe** during a presentation in Birmingham. In parallel, the project was presented at several key events: **oral presentation at EAS in Glasgow**, **moderated poster session at ESC in Madrid**, and poster at the **European Lipoprotein Club in Tutzing**, and at the **ADLM Diagnostic Conference in Chicago**.

A step forward in FH Early Project

Gene Titan, a mass genotyping equipment, has finally been installed at INSA (Instituto Nacional Ricardo Jorge) in early September. The “FHgenID” chip arrays specifically designed for FH diagnosis are now ready. Training and internal validation are the next steps. The main objective of work package 10 is to evaluate how this chip can be a faster and more affordable diagnostic tool for FH.

NETWORK NEWS

Austria - FHchol Austria

Cooking course for FCS on the 7 November 2025 in Vienna

The cooking course is tailored to the needs of FCS patients and is a perfect opportunity to meet other FCS patients, exchange experiences and spend an afternoon cooking FCS-friendly food together. FHchol Austria invites all German-speaking FCS patients to participate!

The cooking course itself is free as it is sponsored by SOBI. Travel costs of up to 150€ are reimbursed for FHchol Austria members – membership fee is 20€ per year. For more info read the **official invitation here** (in German) or contact: **info@fhchol.at**.

France - Anhet.f

France Achieves Major Milestone on FH Screening

After over 4 years of advocacy, our network member **Anhet.f** has achieved **a historic success**: the Haute Autorité de Santé (HAS) has included **universal FH screening** in its **2025-26 agenda**. Announced just before **FH Awareness Day**, this milestone places France among the leading examples in Europe as the EU prepares its Cardiovascular Health Plan. With over 250,000 people living with FH in France—yet only 10% diagnosed—this breakthrough paves the way for early detection, timely treatment, and lives saved.

Ireland - Croí Ireland

Community-Led Health Checks Uncover Cholesterol Risk in Rural Ireland

In Ireland, community health checks led by **Croí**, in partnership with the **Irish Farmers Association**, are uncovering the hidden burden of high cholesterol in rural areas. Nearly half of the participants had elevated cholesterol, and 40% were unaware of their most recent result. With an estimated 20,000 people in Ireland living with **undiagnosed FH**, these findings underline the urgent need for a national FH screening strategy. This initiative shows how community-based testing and GP referrals can support earlier detection and strengthen advocacy at both national and EU levels. **Read more.**

Global: Global Heart Hub

Global Heart Hub's Annual Review 2024

Global Heart Hub is proud to share their Annual Review 2024, marking five years of uniting and amplifying the voice of the global cardiovascular patient community. In 2024, Global Heart Hub expanded its international affiliate network to 130 patient organisations across 42 countries, strengthening the patient voice, raising awareness of the burden of cardiovascular disease and advocating for optimal cardiovascular care worldwide. **Read now**.

PARTNER NEWS

European Society of Cardiology (ESC)

Lipoprotein(a): current role and future perspectives in cardiovascular medicine (free webinar)

Join ESC on **31 October 2025, 18:00-19:00 CET** for a free webinar chaired by Prof. U. Landmesser with leading experts from the US and Europe. Learn about Lp(a) as a genetic risk factor for CVD, current management, and upcoming therapies. Don't miss this chance to understand why wider Lp(a) testing is vital. Learn more and register **here**.

European Stroke Organisation (ESO)

Closing the Gaps in Stroke Care: A Call to Action for Europe

On **14 October 2025**, **Stroke Alliance for Europe (SAFE)** and **European Stroke Organisation (ESO)** will host *"Closing the Gaps in Stroke Care: A Call to Action for Europe"* at the European Parliament in Brussels. Stroke is the EU's second leading cause of death and disability, yet care remains fragmented and under-resourced. The event will highlight urgent gaps and introduce the forthcoming **Stroke Action Plan for Europe (SAP-E)**, a roadmap with evidence-based solutions to strengthen prevention, emergency response, rehabilitation, and long-term support. Learn more.

EURORDIS

Applications Now Open for the 2026 Open Academy Trainings

Applications are now open for the **EURORDIS Open Academy Schools 2026**, taking place **25-28 May in Barcelona (Spain),** offering exclusive learning opportunities in:

- Medicine Research & Development
- Scientific Innovation & Translational Research.

Join a community of 850+ alumni driving change in rare disease advocacy. **Deadline for applications: 17 October 2025.** **Learn more and apply here**.

Take Part in the Rare Barometer Survey – Help Shape the Future of Rare Disease Advocacy!

On 11 September 2025, EURORDIS–Rare Diseases Europe launched a new global Rare Barometer survey to explore what helps people and families live with a rare or undiagnosed condition. Open worldwide in 25 languages, the 20-minute survey runs **until 16 November 2025**. With enough responses per condition (30 or more), **dedicated reports for conditions will be created**, providing unique insights that strengthen advocacy and help drive meaningful change. **Read more** and **take the survey**.

World Heart Federation (WHF)

World Heart Day - 25 Years of Impact

On **29 September**, the world marked the **25th anniversary of World Heart Day** with the theme *"Don't Miss a Beat."* The campaign inspired millions to join the *Keep the Beat Challenge*—25 minutes of activity for 25 days—and called on governments to expand access to life-saving care. While the day is over, the World Heart Federation and its members continue to lead global action against CVD, shaping policy, training healthcare providers, and working to secure affordable medicines for all. Learn more

NEWS FROM AROUND THE WORLD

China

An inaugural patient meeting of FH China

On FH Awareness Day, **FH China hosted its first-ever patient meeting.** The meeting created space for patients to connect, learn and share experiences—an important milestone for the Chinese FH community to raise awareness about familial hypercholesterolaemia (FH) and its rare form, HoFH.

The FH Europe Foundation was honoured to support this initiative. CEO **Magdalena Daccord** delivered a heartfelt message of solidarity on behalf of the international community, underlining our shared commitment to collaboration and better FH care. **Anna Andrea Böhm** from FHchol Austria also joined the event, strengthening cross-border dialogue and highlighting the power of international partnerships.

This milestone marks the beginning of deeper collaboration with FH China, building on connections first made in 2024. Together, we will continue to foster a strong global FH community and work towards better recognition, resources and advocacy worldwide.

Croatia

Croatia Advances Rare Disease Awareness

On 12-13 September 2025, the division of Metabolic Diseases at University Hospital Centre Zagreb, together with the Croatian Society for Rare Diseases and the Ministry of Health Reference Centre for Rare and Metabolic Diseases, hosted the **Croatian Rare Disease Day Symposium** in Split and online. The event brought together clinicians, researchers, patient advocates and policymakers to address challenges in diagnosing, treating and supporting people with rare diseases.

It backed the **initiative to establish 19 September as Croatia's National Rare Disease Day**, and encouraged ongoing engagement through metabolizam.hr. Croatia's collaborative approach shows how partnerships between professionals, patient groups and government can drive real change—a model for rare disease communities across Europe.

KNOWLEDGE HUB

Workshop for Patient Ambassadors: Rules of Engagement

📅 **28 October**
🕓 **13:30-14:30CET**
🔗 **Learn more & Register here**

Join the Patient Engagement Open Forum (PEOF) training event on **28 October, 13:30-14:30 CET Lunch & Learn: Rules of Engagement: Navigating Codes of Conduct for Patient Engagement (II).** This workshop will explore how national codes and shifting regulations shape pharma-patient collaboration. Learn about the role of national trade associations, concrete examples of compliance challenges and solutions, and PE Country Guidelines.

SAVE THE DATE

- **October 27-29:** World Orphan Drug Congress Europe 2025, Amsterdam, The Netherlands
- **November 1:** FCS Awareness Day
- **November 14-16:** FH Europe Foundation Annual Meeting, Zagreb, Croatia
- **December 5-6:** 2025 Global Forum, Glasgow, Scotland
- **December 10-11:** EACH Summit, Brussels, Belgium

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