Welcome to the October edition of Heart Beat News

FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

31 October 2025

October has been an inspiring month for FH Europe: full of connection, collaboration, and progress. From representing patient voices at the **World Orphan Drug Congress Europe 2025** in Amsterdam to preparing for **FCS Awareness Day** on 7 November, we’ve seen the power of partnership across the rare disease and cardiovascular communities.

As we look ahead, we invite you to join us in raising awareness for FCS, continuing to support mental health in the rare disease community, and participating in **Run4FH Europe at our Annual Network Meeting in Zagreb**. Together, we’re driving change — one conversation and one step at a time.

FH EUROPE FOUNDATION NEWS

World Orphan Drug Congress

The FH Europe Foundation took part in the **World Orphan Drug Congress Europe 2025**, hosting a booth for the **first time** at this leading international event. It was a valuable opportunity to engage with patient advocates, healthcare professionals, researchers, and industry partners, all working to advance care for rare diseases.

The booth became a lively meeting point for sharing our work in **rare lipid disorders (HoFH and FCS)**, highlighting projects such as **FH-EARLY**, **PerMed FH**, and **PERFECTO-FH**, and amplifying patient perspectives through our **Ambassadors**, many of whom joined us in person.

The warm welcome from the rare disease community was deeply encouraging and reaffirmed our mission to **amplify patient voices and foster collaboration across sectors**. The energy, openness, and shared commitment to progress made this event a truly inspiring experience. We thank the organisers and everyone who visited for their support and engagement — together, we continue to place patients at the heart of innovation.

Get ready for FCS Awareness Day - 7 November

On **7 November,** we will join the FCS community in marking Familial Chylomicronaemia Syndrome (FCS) Awareness Day. To support engagement, we've created a **dedicated FCS awareness day page** with resources and an awareness toolkit. Explore it to find materials and ideas to get involved. We also invite you to take part in the "**10g Fat Challenge,**" which reflects the daily realities of living with FCS. We invite all Ambassadors and partners to join us in raising awareness and celebrating this important day together.

Visit the dedicated FCS Awareness Day page

World Mental Health Day

On World Mental Health Day, FH Europe Foundation highlighted the vital link between emotional well-being and living with inherited lipid disorders. People affected by conditions such as Familial Chylomicronaemia Syndrome (FCS), Homozygous Familial Hypercholesterolaemia (HoFH), and other inherited risks often face not only physical challenges but also isolation, stress, and anxiety. **Read more**: **Mental Health and Rare Disease: The Hidden Struggle**

We also highlighted the strong connection between **mental and cardiovascular health**, supporting the calls from the **WHO** and **European Society of Cardiology (ESC)** to integrate mental well-being into heart care. Explore why Mental Health Matters for People living with Cardiovascular Risk and Inherited Lipid Disorders **here**.

Learn more about the **EURORDIS Mental Health & Wellbeing Toolkit**, co-created with patients and professionals to strengthen wellbeing in the rare disease community.

World Stroke Day

This World Stroke Day, FH Europe Foundation highlighted how high cholesterol and lipoprotein(a) [Lp(a)] are often hidden risks for stroke. Both can be inherited and go unnoticed without testing. For people living with inherited lipid disorders, early detection, access to treatment, and routine screening are vital. Read more about **cholesterol and stroke risk** and about **Lp(a) as a hidden risk factor**.

And don't forget to support the calls for Lp(a) universal testing: **Brussels International Declaration**

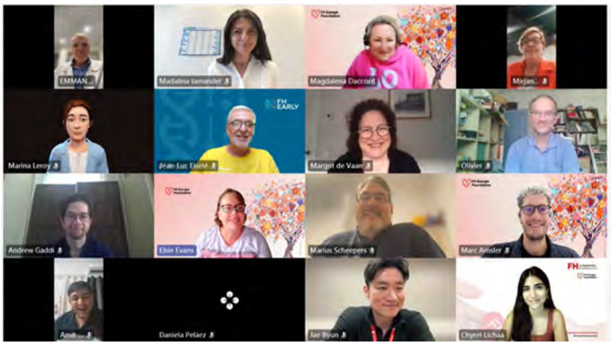
Run4FH Europe at the Annual Network Meeting 2025

Preparations for the FH Europe Foundation Annual Network Meeting, taking place from 14-16 November 2025 in Zagreb, are in full swing. This year, we are not only getting ready for inspiring discussions and collaboration but also lacing up and training for **Run4FH Europe**: a 5 km public run taking place **on Sunday, 16 November at 14:00**. We are proud of this special activity, that is being led by the **Croatian Dyslipidaemia Patients Association**, FH Europe's network member in Croatia and this year´s local co-host.

The event supports the *Hunt for the Silent Killer* campaign, raising awareness of familial hypercholesterolaemia and cardiovascular health. Everyone in Zagreb is warmly invited to join, whether running, walking, or cheering, every step counts! Together, we make a difference.

Register for the run here.

AMBASSADOR PROGRAMME NEWS



Welcoming our new Certified Programme Cohort 2025-26!

We are delighted to welcome the **new cohort of FH Europe's Certified Ambassadors** for 2025-26. This diverse group of individuals—spanning healthcare, education, advocacy, and business—recently came together for an inspiring introductory meeting, united by one shared goal: to drive change for those living with inherited lipid conditions. Their journey builds on the remarkable achievements of our pilot group, who helped shape the programme's structure, content, and accessibility. From contributing to advisory boards and speaking at international forums, to co-developing educational resources and advocating for policy change, the pilot cohort laid a powerful foundation for future Ambassadors to build upon.

As one Ambassador beautifully put it, *"Our group".* This is more than a network; it's a collective force **committed to improving lives through knowledge, action, and shared purpose**. This next generation of Certified Ambassadors is ready to continue that legacy—bringing lived experience and professional insight to the forefront of the wider world.

We invite our wider community to support and engage with this growing group of Ambassadors. Whether by sharing stories, amplifying voices, or collaborating on initiatives, your involvement helps strengthen our collective impact. Together, we can improve care, raise awareness, and advocate for better outcomes for all those affected by inherited lipid disorders.

From Experience to Impact: An Ambassador’s Voice at the GCNLF Summit

Marc Rijken’s participation as an FHEF Certified Ambassador added a deeply personal and powerful dimension to the Global Cardiovascular Nursing Leadership Forum (GCNLF) Summit. By **sharing his lived experience and advocacy journey**, he helped bridge the gap between clinical leadership and patient perspectives—reinforcing the importance of collaboration in transforming heart health globally. **Find out more**

FH Europe Ambassadors and Experts Join EP PerMed Podcast at Prague Conference

On **26-27 November 2025**, the **ICPerMed and EP PerMed Joint Conference** in **Prague** will mark the **10th anniversary** of the Council Conclusions on Personalised Medicine and the first Strategic Research and Innovation Agenda (SRIA). The event will gather leaders, experts, and patients to reflect on progress and the future of personalised healthcare.
FH Europe Foundation will contribute to the **live recording of the EP PerMed podcast “*The Science of You*”**, focusing on personalised approaches in cardiovascular and lipid disorders. Taking part will be **Patient Ambassadors Olivia de Graaff** and **Dianne van Leeuwen**, **CEO Magdalena Daccord**, and **Trustee Prof. Albert Wiegman**.

Find out more

RESEARCH PROJECTS

FH EARLY

FH EARLY Work Package Leaders Meeting

On 13 October 2025, the FH-EARLY consortium met online for its 3rd Work Package Leaders Meeting, bringing together representatives from all active work packages to exchange updates and agree on next steps.

FH Europe Foundation shared the latest progress under WP20 – Communications, Dissemination, Joint Activities (CDJ) and Exploitation, outlining recent highlights including the launch of the **Expert Patient Panel** (EPP) and the **European Parliament event in September**. Both milestones have helped raise the project's profile and strengthen its visibility and impact within the European cardiovascular community.

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perfecto
Preventing the Preventable

PERFECTO highlights equity in FH genetic testing at ERN ITHACA webinar on unique populations

On 14 October, Tomas de Jong from the European Public Health Alliance (EPHA) represented PERFECTO at a European Reference Network ITHACA webinar on "**Genetics and unique populations – the case of Finnish, Roma and Irish Traveller communities**." The event explored how genetic and screening needs differ across Europe and how EU policy can reduce inequities.

EPHA highlighted how EU initiatives address **health equity through the social determinants of health, inclusion frameworks, and data governance**. Barriers such as low trust, limited clinic access, and funding gaps often prevent vulnerable groups from accessing genetic testing.

PERFECTO offers practical solutions, including improved FH paediatric screening (WP2), personalised communication models (WP3), and community mediation among Roma and migrant groups (WP4). Early results show persistent inequities in access, literacy, and gender. Together, these efforts demonstrate how policy and practice can make genetic screening more inclusive and ensure no population is left behind.

EP PerMed
European Partnership
for **Personalised Medicine**

Share Your Voice – EP PerMed Survey on Personalised Medicine

FH Europe Foundation is proud to be part of the **Advisory Board of the EP PerMed project**, with our CEO Magdalena Daccord contributing to the initiative on behalf of the Foundation. The project is now running a **survey on citizen awareness of Personalised Medicine (PM)**, an approach that tailors prevention, diagnosis, and treatment to each individual. For our community, PM offers great potential for improving the management of inherited lipid conditions like **familial**

hypercholesterolaemia (FH). The survey is anonymous, takes just 10-15 minutes, and is available in multiple languages. **Take the survey**

NETWORK NEWS

Luxembourg

Universal paediatric FH Screening started today in Luxembourg

Luxembourg will be introducing a **national screening programme for Familial Hypercholesterolaemia (FH)** from just 18 months of age from mid November on, a major milestone in preventive cardiometabolic medicine.

Led by **Prof. Carine de Beaufort** and **Dr Marianne Becker**, this initiative brings science into action, enabling early diagnosis, lifestyle guidance, and treatment from infancy. Parents will receive invitations from 17 November and can book free testing via **MyGuichet.lu**.

Find out more

Check the informational brochure

Hungary - SZÍVSN

Celebrating Heart Health Advocacy in Hungary

We’re thrilled to spotlight the incredible work of our network member in Hungary, who hosted a vibrant **World Heart Day Central Event**. Held at a prestigious venue, the event featured a dynamic programme including our very own **Heartily Hungary** panel discussion, which brought together voices from across the cardiovascular community. One of the standout moments? A panel featuring **actual Hungarian astronauts**, adding a truly stellar touch to the day!

Read more.

Italy - AISC

11th National Congress of AISC – New Models of Community Care and Cardiovascular Research

On **25 October 2025**, the **Italian Association of Heart Failure Patients (AISC)** held its **11th National Congress** in **Naples**, focusing on *“New Models of Community Care and Cardiovascular Research: The Patient’s Perspective.”* Chaired by **Dr. Rossana Bordoni** and **Prof. Salvatore Di Somma**, the event brought together healthcare professionals, institutions, and patients to explore innovative care models, prevention strategies, and patient-centred research. A key highlight was the announcement of a **new partnership with the Indonesian Association for Cardiovascular Patients**, strengthening global collaboration in cardiovascular advocacy and care.

Global - Global Heart Hub

Unite Annual Summit in Dublin with a spotlight on Women´s Cardiovascular Health

From 2 to 4 November 2025, the Global Heart Hub will host its **Unite Annual Summit** in Dublin, Ireland, bringing together patient organisations, clinicians, researchers, and advocates from around the world. This year’s meeting will focus on **women’s cardiovascular health**, highlighting the urgent need to address inequalities in diagnosis, research, and access to care.

The programme will feature engaging panel discussions and presentations, including contributions from **FH Europe Foundation CEO Magdalena Daccord**, **Policy Manager Kitty Daccord**, and **Patient Ambassadors**, who will share their insights and lived experiences. Through dialogue, shared experience, and collaboration, participants will work together toward **concrete actions to improve outcomes for women globally**. Learn more

PARTNER NEWS

European Alliance for Cardiovascular Health (EACH)

EACH Cardiovascular Health Summit: 10-11 December in Brussels

The **European Alliance for Cardiovascular Health** invites health stakeholders, policymakers, and national representatives to the EACH Cardiovascular Health Summit, taking place in **Brussels on 10-11 December 2025**. Organised with Secretariat support from the **European Society of Cardiology**, this inaugural event will spotlight national cardiovascular action plans, emerging science in prevention and risk management, and patient perspectives shaping the **EU Cardiovascular Health Plan**.

FH Europe Foundation will be represented by **Kitti Almer**, Policy and Advocacy Manager, speaking at the High-Level Panel on addressing inequalities and improving equity through EU and national cardiovascular health action plans, and by **Marc Rijken**, Patient Ambassador, contributing to the session "*Patient Voices in Action: How Lived Experience Can Guide a Transformative EU Cardiovascular Health Plan*."

Find more information and the full programme here.

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**.

EURORDIS

Share Your Experience: EURORDIS Rare Barometer Survey Open Until 16 November

EURORDIS-Rare Diseases Europe has launched a new **Rare Barometer survey** to better understand the daily realities of people living with rare or undiagnosed conditions such as **HoFH** or **FCS**. The survey explores how these conditions affect well-being, learning, work, and participation in community life. By sharing your experience, you help shape future policies and support for the rare disease community. The survey is available in **25 languages** and takes about **20 minutes** to complete.
Take part before 16 November: tiny.cc/RB-MH-info

NEWS FROM AROUND THE WORLD

China

FH China releases 2025 Report of Psychosocial Status in individuals with HoFH

On **20 September**, during the inaugural **FH Conference**, **Homy FH China Patient Network** and **Associate Professor Zhang Yudi** (University of Science and Technology Beijing) released the **2025 Report on Psychosocial Status in Individuals with HoFH**. The study explores stigma, life satisfaction, and sense of meaning in life among adults living with **homozygous familial hypercholesterolaemia (HoFH)**. Findings show low overall psychosocial adaptation, high self-stigma, and moderate life satisfaction, highlighting the need for greater awareness and psychosocial support. **Learn more**

FH China patient network hosts the first FH conference and integrated patient support event

On **20 September**, the **Homy FH China Patient Network**, with support from the **Chinese Organization for Rare Diseases (CORD)**, held the **first FH Conference and Integrated Patient Support Event**. The meeting brought together leading FH experts, scholars, patients, families, and industry representatives to discuss care, treatment, and public health approaches for **familial hypercholesterolaemia**. Alongside expert sessions, patient-focused activities included a **Mental Wellness Workshop**, **CPR training**, and a **City Tour in Wuhan**, fostering connection and empowerment within the FH community. **Learn more**

KNOWLEDGE HUB

EUPATI Training on Patient Involvement in European HTA - 18 November

📅 **18 November**
🕔 **17:00-19:00 CEST**
🔗 **Learn more & register here**

EUPATI will hold an online training session on the European Health Technology Assessment Regulation (EU HTAR) on 18 November, 17:00-19:00 CEST. Led by Dr. Carolyn Ingram (NCPE, Ireland), the session will provide participants with an overview of EU HTAR and its relevance to patient engagement in healthcare decision-making. The course, delivered in English with certification available upon feedback, is open to those active in HTA or interested in strengthening patient representation.

New ICD-10 Code Brings Greater Recognition for HoFH Patients

A major milestone for the **HoFH community**: a **dedicated ICD-10-CM code (E78.010)** for **Homozygous Familial Hypercholesterolaemia (HoFH)** was officially approved and took effect on **1 October 2025**.
This new code ensures more accurate diagnosis, improved insurance coverage, and stronger research data — helping identify HoFH patients more precisely and support tailored treatment. It also reinforces advocacy and awareness efforts by recognising HoFH as a distinct condition.
This achievement reflects years of collaboration among patients, clinicians, researchers, and organisations, marking a meaningful step toward better care and visibility for people living with HoFH.

Modern Science Transforms Care for Familial Hypercholesterolaemia

A new **review** in *The Lancet Diabetes & Endocrinology* brings together the **latest advances in the understanding and care of familial hypercholesterolaemia** (FH).
The authors highlight how **growing access to genetic testing, refined screening approaches**, and powerful new cholesterol-lowering therapies (such as PCSK9 inhibitors and other emerging agents) are reshaping clinical practice. They also emphasise the **crucial role of early detection** and **family-based screening in preventing cardiovascular complications**. Together, these developments mark a turning point in FH care, showing how modern research is translating into more precise diagnosis, personalised treatment, and better long-term outcomes for patients and their families.

SAVE THE DATE

- **November 7: FCS Awareness Day**
- **November 14-16: FH Europe Foundation Annual Meeting**, Zagreb, Croatia
- **November 26-27: EPF Congress**, Brussels, Belgium
- **December 5-6: 2025 Global Forum**, Glasgow, Scotland
- **December 10-11: EACH Summit**, Brussels, Belgium

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