FH Europe Foundation

Heart Beat News

2 November 2026

October has been a month of meaningful connections and new achievements for our community! From our Ambassadors sharing their experiences at the **World Orphan Drug Congress** and **International Lipid School** to new research on the impact of HoFH on quality of life, patient voices continue to make a difference. Across our network, organisations have also been raising awareness, advancing research and bringing cardiovascular prevention closer to their communities. And now, all eyes are on **Dublin**, where our **Annual Network Meeting** (6–8 November) will bring us together, alongside **FCS Awareness Day**. We can't wait to see many of you there!

FH EUROPE FOUNDATION NEWS



ANM in Dublin

From **6–8 November**, the FH Europe Foundation community will gather in Dublin, Ireland, for our Annual Network Meeting, organised with local co-host **Croí**. Bringing together patient advocates, healthcare professionals, researchers and partners, the event will offer opportunities to exchange experiences, strengthen collaboration and advance our shared priorities for inherited lipid disorders. Can't join us in Dublin? Follow the discussions online!

- **Register for online participation**
- **Discover the programme and event details**



FCS Awareness Day

6 November marks FCS Awareness Day, and this year it coincides with the opening day of our Annual Network Meeting in Dublin, bringing an additional opportunity to amplify the voices of people living with Familial Chylomicronaemia Syndrome (FCS). In partnership with **Rare Revolution Magazine**, we will take part in their **Takeover Tuesday** on 3 November, sharing patient stories through their social media channels. These personal experiences will highlight the realities of living with FCS, the challenges faced by patients and families, and the importance of earlier diagnosis, better understanding and access to appropriate care.

Our new FCS Awareness Day toolkit is also available, with ready-to-use visuals and messages to help our community raise awareness and spread the word. **Explore the toolkit**, share the stories and help make FCS more visible!

World Orphan Drug Congress

FH Europe Foundation participated in the **World Orphan Drug Congress** in Amsterdam on 27–28 October, with a dedicated **booth** and the presence of several of our **Ambassadors**, bringing patient voices and lived experiences into discussions on rare diseases. **Marina Leroy**, our scientific communications manager, also contributed to a panel exploring the **true economic impact of living with a rare disease** and how regional experiences can inform global action. The discussion highlighted the importance of considering both the financial and non-financial burden on patients and families to support evidence-based advocacy and more patient-centred policies and solutions.

Procardio - Interconnected Nature of Cardiovascular, Kidney and Metabolic Health

What initially appeared to be a highly specialised scientific meeting turned out to be an inspiring and thought-provoking experience for FHEF! The **14th international proCardio symposium**, hosted by Roche Diagnostics in Basel, brought together approximately 150 clinicians, researchers and experts to explore advances in cardiovascular-kidney-metabolic health, diagnostics and prevention. Representing FHEF, **Magdalena Daccord** contributed to the closing panel alongside **Prof. Christie Ballantyne** and **Dr Berkan Kurt**, moderated by **Manjusha Chatterjee**, highlighting how patient advocacy, scientific evidence and international collaboration can shape health policy. The work of the **Lp(a) International Task Force**, the **Brussels Declaration** and recent EU cardiovascular policy developments provided tangible examples. Beyond the scientific updates, the meeting reinforced the importance of looking at health more holistically, connecting medical specialties and recognising patients and advocates as essential partners in research, prevention and implementation.

Read the full article to discover the key insights from proCardio 2026.

MOSAIC 2026: Looking Beyond Individual Diseases

What happens when research looks beyond individual organs and considers how different conditions interact? MOSAIC 2026 highlighted the importance of more integrated approaches to understanding complex health conditions. Elsie Evans represented FH Europe Foundation as a speaker, bringing the patient perspective into discussions on multidisciplinary research, personalised care and the challenges of living with multiple conditions. **Read our blog**

Lp(a)HORIZON: FHEF Shares Officials Novartis Letter to the Patient Community

On 16 October 2026, FEF received an official letter from Novartis addressed to patient organisations and patient advisors, confirming the **discontinuation of its pelacarsen development programme** following the **Phase III Lp(a)HORIZON** topline announcement in September. At Novartis's request, FHEF is sharing this letter with the wider patient community, reflecting the company's own communication and decisions. Alongside the letter, we provide background on the announcement, the independent response of the **Lp(a) International Task Force** and the additional steps FHEF is taking in the interests of our community. These include discussions with Lp(a) Ambassadors and scientific experts, as well as a planned public webinar following the presentation of detailed trial findings on 7 November. **Read the full update and Novartis letter on our website**

AMBASSADOR NEWS



Seven Ambassadors Bring Patient Voices to the International Lipid School

From 15–18 October 2026, **FHEF Patient Ambassador**s took centre stage at the 6th Lipid School in Split, Croatia, bringing lived experience directly into scientific sessions alongside leading international experts. Representing HeFH, HoFH, elevated Lp(a), FCS and LAL-D, our Ambassadors shared their personal and family journeys with almost 60 medical and pharmacy students, young clinicians, researchers and specialists. The School offered a rare opportunity for participants to learn directly from people affected by some of the rarest inherited lipid conditions, while enabling our Ambassadors to deepen their scientific knowledge and build new connections. Beyond the lecture hall, the ***"Hunting the Silent Killer"*** campaign brought free cardiovascular health checks to the local community, putting our **#KnowYourNumbers** message into practice. A wonderful example of science, patient expertise and community prevention coming together. Big policies. Small communities. Real people. Real action!
Read the full story



Our Ambassadors Bring Patient Voices to the World Orphan Drug Congress

Our Ambassadors **Margot de Vaan** and **Marc Rijken** joined FH Europe Foundation at the World Orphan Drug Congress in Amsterdam on 27–28 October. They had the opportunity to meet participants, share their personal experiences and bring a patient perspective to conversations about living with rare and inherited lipid disorders. **A big thank you to our Ambassadors** for taking the time to connect with others and share their stories!

Congratulations to Renate on Completing the EUPATI Training!

Congratulations to **Renate Kaal** on successfully completing the 14-month **EUPATI Patient Expert Training Programme**! This achievement reflects her commitment to strengthening patient involvement in medicines research and development. We look forward to seeing her put this expertise into practice and continue contributing to our community as a trained patient expert.



RESEARCH PROJECTS

PerMed FH Event

The **International Symposium on Personalised Medicine in Familial Hypercholesterolaemia** will take place on **3–4 December 2026** in Sintra, Portugal. Bringing together researchers, healthcare professionals and patient advocates, the event will explore advances in early diagnosis, personalised treatment and cardiovascular prevention. FH Europe Foundation will contribute to the discussions, ensuring the patient perspective is represented. Online participation is free and open to everyone, with registration required. **Register here**

PERFECTO and FH-EARLY Presentations at the Geneva Health Forum

FH-Early and **PerMedFH** have reached an important milestone with their first joint research publication in ***Atherosclerosis***. The study compared two laboratory methods for assessing how changes in the **LDL receptor gene** (LDLR) affect its function. The findings support giving greater weight to microscopy-based evidence when interpreting genetic variants. This could help clarify variants of uncertain significance and, ultimately, support more accurate genetic diagnosis of familial hypercholesterolaemia (FH). **Read the study**

JACARDI General Assembly: Turning Shared Learning Into Lasting Impact

The **JACARDI** General Assembly in Poznań, Poland, brought partners together to share progress and lessons from **cardiovascular disease and diabetes pilot initiatives** across Europe. Discussions focused on **prevention, early detection, integrated care and patient self-management**, with particular attention to equity, inclusion and community engagement. A key message was that early detection must be followed by appropriate care and support. Partners also explored how collaboration with healthcare professionals, policymakers and patient organisations can help sustain successful approaches beyond the project.

FH Europe Foundation Joins New European AI Research Project

A new European research project, **MCMT-AI (Multimodal CardioMetabolic Twin)**, has received funding through EP PerMed, with FH Europe Foundation joining the consortium. The project will develop and test an **AI-powered digital twin** combining clinical data, wearable technologies and patient-reported information to support more personalised care for people living with multiple cardiometabolic conditions. By exploring better risk assessment, treatment decisions and earlier detection of complications, MCMT-AI aims to improve care while ensuring patient perspectives help shape the development and implementation of these innovative tools. Stay tuned!

NETWORK NEWS





Austria: FHchol Austria

FHchol Austria Celebrates 15 Years of Patient Advocacy

FHchol Austria celebrated its **15th anniversar**y during its General Assembly and Patient Conference in Vienna, bringing together members, experts and partners. Highlights included the appointment of **Gersina Rega-Kaun as Head of the Scientific Board**, the **recognition of founder Prof. Kurt Widhalm** as an honorary member, and the presentation of the **Gaby Hanauer-Mader Award 2026** to Monika Chocholous. Expert presentations covered the Austrian FH registry and the latest national lipid consensus. Elsie Evans represented FH Europe Foundation, joining the celebrations and recognising 15 years of commitment to the FH community. **Read Elsie's blog post about the event**.

China: Hongmili FH China Patient Network

Hongmili FH China: Bringing Patient Voices into Innovation and Storytelling





On October, **Hongmili FH China Patient Network** brought the patient perspective to the **Rare & Boundless Innovation Carnival** in Hangzhou, where Nazhen Chen moderated a discussion on making technological innovation, including AI diagnostics, more accessible to patients. The organisation also launched a **HoFH patient storytelling project**, filming a short documentary about an adult patient's journey towards diagnosis and care. The film is expected to be released around Rare Disease Day 2027, helping raise awareness through lived experience.

Greece: LDL Greece

LDL Greece Brings the Patient Perspective to Lipid Conference



On 9–10 October, **LDL Greece** participated in a **regional conference on cardio-renal-metabolic health** in Thessaloniki. During a roundtable with healthcare professionals, representatives shared their experiences of living with and caring for someone with FH, highlighting everyday challenges, treatment developments and patient needs. This marked the organisation’s fourth consecutive participation, reflecting growing recognition of the importance of patient involvement and collaboration with the medical community.

Iraq: FH Iraq

Dyslipidaemia Awareness TV Interview

FH Iraq recently participated in a **Kurdish-language television interview** to raise awareness of dyslipidaemia, address common misconceptions and highlight the importance of early detection and cardiovascular disease prevention. By engaging with established local television channels and media platforms, the organisation continues to reach wider audiences across the Kurdistan Region of Iraq, helping communities better.

Netherlands: Stichting VrouwenHart

Highlighting the Power of Patient-Led Advocacy



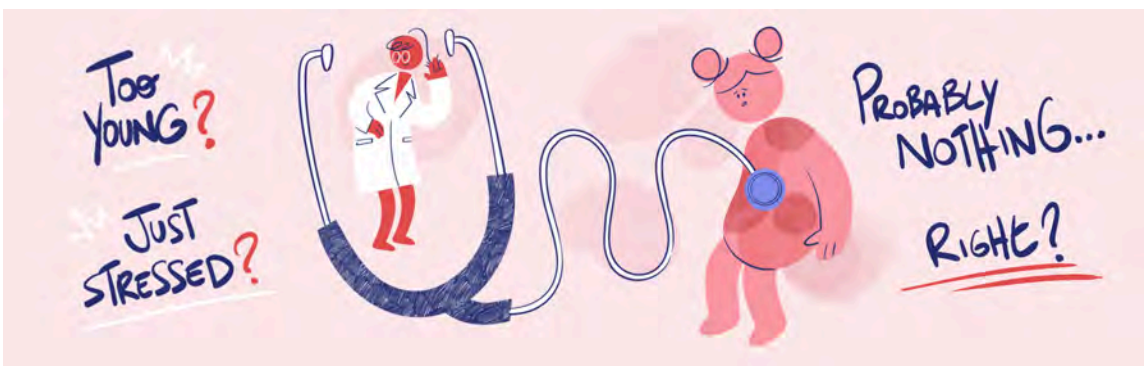
On 12 October, **Stichting VrouwenHart** spoke at a ZonMw event in the Netherlands, where **two reports on women’s and girls’ experiences of healthcare** were presented. Represented by board member Renate Kaal-Poppelaars, the organisation shared how a small patient group, supported by 15 volunteers and virtually no structural funding, has built a community of around 30,000 followers. Its experience highlights the impact of patient-led advocacy and lived experience, while reinforcing the need for sustainable resources to strengthen patient organisations and amplify their voices. **Read more**

UK: Heart UK

Heart UK Welcomes New Chief Executive

John Orchard joined **HEART UK** as Chief Executive on 6 October, succeeding Jules Payne, who is retiring after many years of dedicated leadership. Bringing extensive experience across the healthcare and charity sectors, John will build on HEART UK's work in cholesterol awareness, cardiovascular prevention and patient support. **Congratulations** to John on his appointment, and **warm thanks to Jules** for her longstanding commitment to the FH and wider lipid community!

PARTNERS NEWS



European Alliance of Cardiovascular Health (EACH)

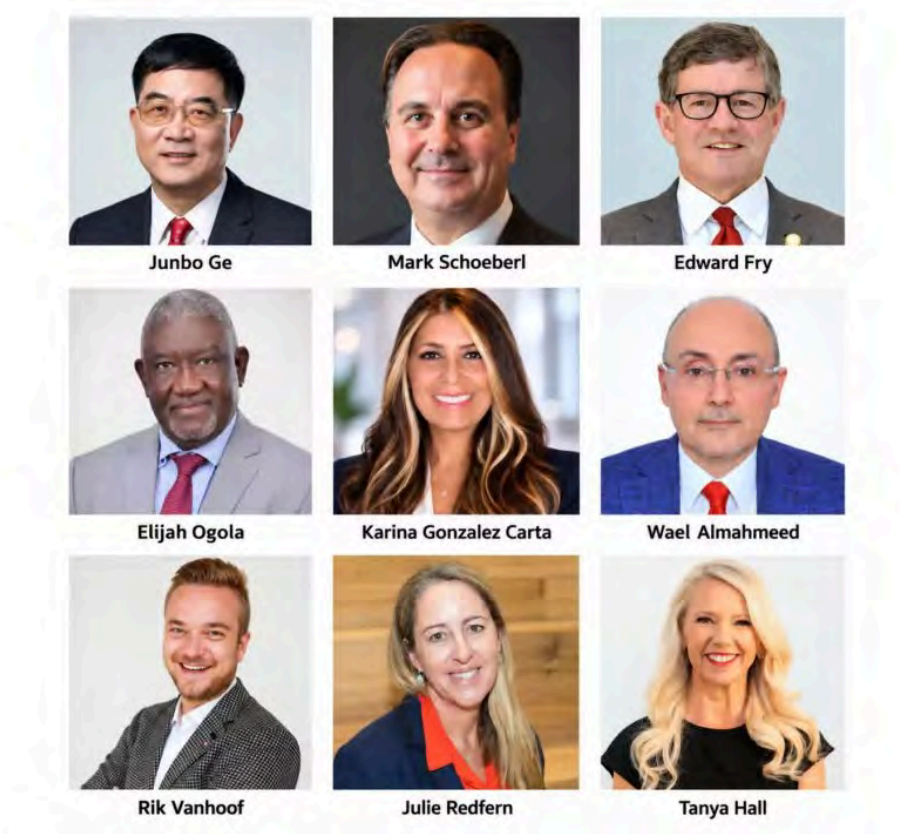
EACH Campaign: Look Beyond the Usual

Launched on **World Heart Day**, the **European Alliance for Cardiovascular Health (EACH)** campaign ***Look Beyond the Usual*** challenges the misconception that cardiovascular disease only affects older people. Targeting healthcare professionals, particularly those in frontline and emergency care, the campaign encourages them to l**ook beyond age and appearances** when assessing symptoms. With its message “***Pause. Reconsider. Reassess.***”, it highlights the importance of early recognition, appropriate assessment and avoiding missed or delayed diagnoses in younger people. **Discover the campaign**

Rare Diseases International (RDI)

Applications Open: RDI Youth Leadership Programme 2027–2028

Rare Diseases International (RDI) is inviting young rare disease advocates to apply for its 2027–2028 Youth Leadership Programme. Over two years, participants will develop leadership skills through mentoring, training and peer learning, while connecting with young advocates worldwide and contributing to global rare disease advocacy. Applications close on **22 November 2026**. **Learn more and apply**



World Heart Federation (WHF)

World Heart Federation Announces New Board for 2027–2028

The **World Heart Federation** has announced the results of its Board elections for 2027–2028, with **Junbo Ge (China)** elected **President**-Elect and **Mark Schoeberl (USA) Vice President**-Elect, alongside a new Treasurer and six Members at Large. The newly elected members will take office in January 2027. **Congratulations** to all! We look forward to continued collaboration to advance cardiovascular prevention, equitable access to care and patient-centered policies worldwide. **Discover the newly elected Board members**

NEWS FROM AROUND THE WORLD

UK: Another Steps Forward for FCS Treatment Access

October brought significant progress for people living with **familial chylomicronaemia syndrome** (FCS) in the UK. Following approvals in the US and EU, the MHRA approved plozasiran on 19 October. Shortly afterwards, NICE recommended both **plozasiran and olezarsen** for NHS use in England, for adults with genetically confirmed FCS whose response to dietary management and conventional triglyceride-lowering treatments has been inadequate. These developments represent an important step towards improving access to treatment options for this rare condition.

Read the NICE guidance on **plozasiran** and **olezarsen**.

US: New AHA Guidance on Women's Cardiovascular Health

A new American Heart Association scientific statement calls for a **more personalised approach to cardiovascular prevention and care for women** throughout their lives. It highlights the importance of considering hormonal changes, pregnancy, menopause and psychosocial health in cardiovascular risk assessment, alongside better coordination between healthcare professionals. **Read the scientific statement**

KNOWLEDGE HUB

PatientView Report: Giving Patients a Seat at the Table

A new PatientView report, ***A Seat at the Pricing Table***, explores how patient organisations advocate for access to medicines, drawing on responses from **2,262 patient groups across 100 countries**. FH Europe Foundation contributed to this international research, which highlights the role of patient organisations in regulatory decisions, health technology assessment and reimbursement processes. Notably, **only 23% reported participating in HTA and reimbursement reviews**, reinforcing the need for stronger patient involvement in decisions affecting access to treatment. **Explore the report and key findings**

EURORDIS European Blueprint for Rare Diseases

The new European Blueprint for Rare Diseases, developed under the leadership of **EURORDIS**, sets out **18 priority actions** to improve diagnosis, access to specialist care, research and social inclusion. FH Europe Foundation contributed through the **European Regional Task Force**, bringing the perspectives of people living with inherited lipid disorders into discussions shaping future European and global rare disease policies. What does this mean for our community, and how can patient voices help drive change? **Read our latest blog**

Help Shape the WHO Global Action Plan on Rare Diseases

The World Health Organization (WHO) is preparing a **public consultation on its Global Action Plan on Rare Diseases**, offering an opportunity for patients and organisations to help shape future global priorities. Rare Diseases International (RDI) is coordinating community input through regional consultations, surveys and stakeholder discussions. To learn how to contribute, join one of RDI's information sessions on 10 November, at 10:00 or 16:00 CET. **Learn more and register**

EURORDIS & EUPATI: Training Opportunities for Patient Advocates

EURORDIS and **EUPATI** offer training opportunities to strengthen patient involvement in research, medicines development and healthcare decisions. Discover the upcoming programmes and develop your skills as a patient advocate. Explore:

- **EURORDIS Open Academy**
- **EUPATI Training**

New Publication: The Impact of HoFH on Quality of Life

A new study published in Patient Preference and Adherence, led by **Elsie Evans** and co-authored by FHEF colleagues, explores the impact of **HoFH and lipoprotein apheresis** on patients and caregivers. The findings highlight reduced quality of life and the significant time and financial burden of lipoprotein apheresis, reinforcing the importance of looking beyond cholesterol levels to understand patients' everyday experiences. **Read the publication**

Last Chance to Join PatientAdvocacy.Academy 2026!

Following FH Europe Foundation Ambassadors can still join the November cohort of **PatientAdvocacy.Academy** **2026 until 10 November**. Can't make it this month? A second cohort offering the same programme will begin in late January 2027. Interested? Get in touch with us as soon as possible! Send an email to **elsie@fheurope.org**.

SAVE THE DATE

- **6 November: FCS Awareness Day**
- **6-8 November: FHEF Annual Network Meeting**, Dublin, Ireland
- **10-12 November: Geneva Health Forum**, Geneva, Switzerland
- **3-4 December: PerMed FH Symposium**, Sintra, Portugal

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