Welcome to the July 2026 edition of Heart Beat News

FH Europe Foundation

31 July 2026

Summer may be in full swing, but our community hasn't slowed down. This past month has brought encouraging developments, from potential new lipid-lowering treatment options and new publications shaping cardiovascular care to preparations for the ESC Congress and the EU Screening Week. As we look ahead, the second half of the year promises to be just as busy, with the our Annual Network Meeting in Dublin, upcoming awareness campaigns, and important policy milestones. We hope you enjoy this latest edition of Heart Beat.

FH EUROPE FOUNDATION NEWS

Get involved in EU Screening Week 2026!

The European Commission is preparing the first EU Screening Week, taking place from **29 September to 4 October 2026** and linked to **World Heart Day**, the EU Safe Hearts Plan and the Know Your Numbers campaign. Organisations across Europe are encouraged to participate through health checks, awareness activities, webinars, community outreach and the promotion of existing screening programmes. Beginning **only five days after FH Awareness Day**, this is an important opportunity to highlight early, life-course screening for

inherited lipid disorders—including FH and elevated Lp(a)—and to turn European prevention ambitions into practical national and local action.

Discover how your organisation can participate and read the full update.

Join Our Community Calls for FH Awareness Day

Preparations for **FH Awareness Day** (September 24th) are underway, and we'd love to have you involved! Join one of our upcoming community calls to learn more about this year's campaign, discover the planned activities, and explore how you and your organisation can help raise awareness and get involved.

🗓️ **18 August, 5:00 pm (CEST) – Register here**
🗓️ **25 August, 12:00 noon (CEST) – Register here**

ESC Congress 2026

FH Europe Foundation will be attending the **ESC Congress 2026** in Munich, joining thousands of cardiovascular professionals, researchers and patient advocates from around the world to discuss the latest advances in cardiovascular health. Throughout the congress, we will be sharing highlights from key sessions, including our CEO **Magdalena Daccord's** presentation, as well as updates from the **Lp(a) International Taskforce** and other developments relevant to the inherited lipid disorder community.

Follow us on our social media channels throughout the congress for live updates, insights and key take-home messages.

Meet FH Europe Foundation at the WODC Europe 2026

After a successful 2025 participation, FH Europe Foundation will once again be attending the **World Orphan Drug Congress Europe in Amsterdam** this

October. Visit us at our exhibition booth and join our dedicated session—more details coming soon.

❗ We also have a limited number of complimentary congress passes available for our community. Interested in attending? Click the button below to get in touch.

Request a complimentary pass

Black Pearl Awards 2027: Nominate the Rare Disease Champions

There is still time to get involved in the **EURORDIS Black Pearl Awards 2027**. We encourage you to **nominate outstanding individuals or organisations** who have made a real difference to the HoFH, FCS or wider rare disease community through advocacy, research, policy, awareness or patient support. We are also inviting **nominations for two FH Europe Foundation Ambassadors**—one representing the HoFH community and one representing the FCS community—to attend the Awards Gala in Brussels on behalf of our community. Together, let's ensure the voices of people living with rare inherited lipid conditions are recognised and represented

Submit a nomination to EURORDIS Black Pearl Awards

Nominate the Ambassadors to attend the Gala in Brussels

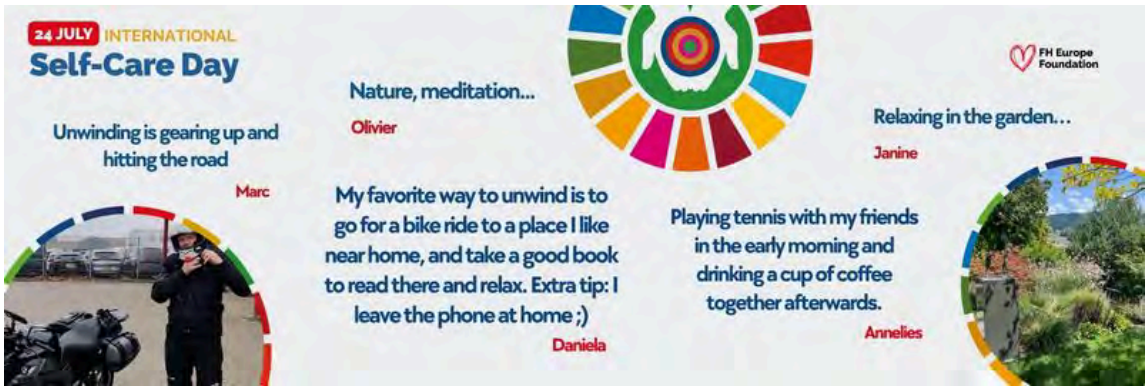
AMBASSADOR NEWS

Summer Campaign - Travel Well with Confidence

Summer is a time to explore, relax and create new memories—but for people living with an inherited lipid disorder, travelling often requires extra planning. Throughout the summer, our Patient Ambassadors are sharing **practical tips**

and personal experiences to help others travel with confidence. From researching nearby medical facilities and checking that treatments can be carried across borders, to packing suitable snacks and preparing for unexpected situations, their advice highlights the real-life challenges—and practical solutions—of travelling with a chronic condition.

Follow us on **LinkedIn**, **Facebook**, and **Instagram** throughout the summer to discover their tips and learn from the experiences of people who understand what it takes to travel with confidence.



International Self-Care Day

On International Self-Care Day, our Ambassadors and members of the wider FH Europe Foundation community came together to share the small habits, routines and reminders that help them look after their **physical and mental wellbeing**. Whether it's listening to your body, making time to rest, asking for support or simply enjoying life's small moments, their messages are a reminder that **self-care is not a luxury**—it's an essential part of living well with an inherited lipid disorder.

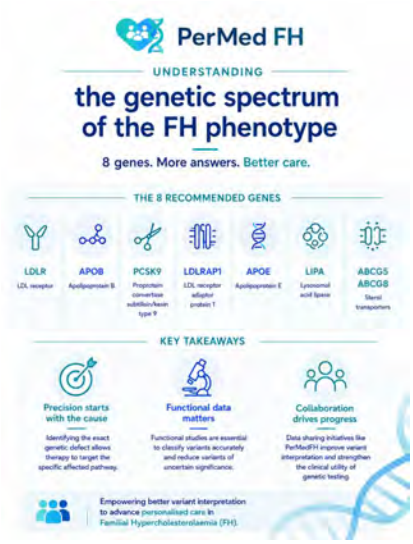
RESEARCH PROJECTS

PerMed FH

Advancing Precision Medicine in FH

A new **review** by **Prof. Mafalda Bourbon and colleagues** explores how advances in genetic testing are improving the diagnosis and personalised management of FH. The article

highlights the growing importance of broader genetic testing panels to distinguish FH from other inherited lipid disorders with similar clinical features, paving the way for **more accurate diagnoses and better-tailored care**.



It also recognises the contribution of **PerMed FH** in advancing **variant interpretation and precision medicine** through international collaboration and the integration of genetic, functional and clinical data. Congratulations to all the authors on this important contribution to the future of personalised care for people living with FH.

NETWORK NEWS

Belgium: Belgian Heart League

2nd Cardiac Patient Day

In June, the **Belgian Cardiac League** successfully hosted its **2nd Cardiac Patient Day**, bringing together more than 100 participants in Ghent and Liège for a day of learning, discussion and mutual support. The programme featured expert talks on the latest developments in cardiology and the importance of mental health after cardiovascular disease, followed by engaging Q&A sessions. The event concluded with inspiring patient stories, highlighting resilience, hope and life beyond a cardiovascular diagnosis. Building on the success of this year's edition, the Belgian Cardiac League looks forward to expanding the event to other regions next year.

Patient Story Podcast: Living with HoFH

In a powerful new testimonial, **Marjorie** shares her experience of living with **HoFH** and the devastating consequences of delayed recognition and inadequate treatment. By the age of 46, she had experienced **12 heart attacks**, undergone the placement of **13 stents** and **triple bypass surgery**. Today, LDL apheresis has become a lifeline, helping to significantly reduce her cholesterol levels. Through her story, Marjorie highlights the importance of timely diagnosis, access to appropriate treatment, and the invaluable support of healthcare professionals, family and loved ones. She also calls for greater awareness of HoFH and wider cholesterol screening to prevent this **"silent killer"** from causing irreversible harm. **Listen to the podcast (in French) here**.

China: FH China

New Report Highlights the Reality of HoFH in China

The **Homy FH China Patient Network** has released key findings from a new report highlighting the significant challenges faced by people living with **HoFH** in China. Drawing on clinical data from 126 patients and a survey of 116 families, the report reveals long diagnostic delays, very low rates of LDL-C control despite intensive treatment, and substantial financial barriers to care. By documenting these real-world experiences, the initiative aims to raise awareness of HoFH and support policy changes that improve earlier diagnosis, access to treatment and long-term care for people living with this rare condition. The full report is expected to be published in **Q3 2026**.

Homy FH China Patient Network Receives National Recognition

Congratulations to the **Homy FH China Patient Network**, which has been awarded the **Qiming Zhuguang Award for Scientific Research Progress** at the 2026 China National Rare Disease Patient Organization Network Annual Conference. The award recognises the organisation's outstanding contributions to advancing FH research and patient care, including the development of a national patient registry, support for research, patient-centred studies, clinical trial facilitation, advocacy for access to new treatments and reimbursement, promotion of LDL apheresis, public awareness initiatives, international collaboration and the organisation of China's first national FH Conference.

France: Ahnet.f

France Adopts Landmark FH Screening Legislation

France has taken a major step forward in cardiovascular prevention by adopting new legislation introducing **universal screening for FH from the age of 6** as part of a national cardiovascular and neurovascular disease prevention strategy. This landmark achievement reflects years of advocacy by **Anhet.f**, the French FH and Lp(a) patient organisation alongside healthcare professionals, researchers and policymakers. The new law represents an important milestone not only for France but also for Europe, demonstrating how early detection can

be translated into national policy and bringing us one step closer to making paediatric FH screening a standard of care across the continent.

Netherlands: Stichting LEEFH

Record Year for FH Detection in the Netherlands

Congratulations to **Stichting LEEFH** on achieving its **highest number of FH diagnoses** since the organisation was founded. This milestone highlights the power of collaboration and the impact of early detection initiatives. Particularly encouraging is that **45% of the newly identified family members were aged 18 years or younger**, reinforcing the importance of identifying FH early to enable timely treatment and help prevent future cardiovascular disease.

New Faces and Fresh Content

Stichting LEEFH is expanding both its **community outreach and scientific expertise**. Ashley, a young person living with FH, has launched a series of engaging **Instagram** and **TikTok** videos sharing practical tips and real-life experiences of living with FH, with more content—including collaborations with FH Europe Foundation Ambassadors—coming soon. The organisation has also welcomed **Prof. Kees Hovingh** as its new Medical Advisor, further strengthening its leadership in FH research and patient care.

PARTNER NEWS

World Heart Federation (WHF)

Cardiac Rehabilitation Roadmap

The **World Heart Federation** Cardiac Rehabilitation Roadmap redefines cardiac rehabilitation as a lifelong approach to cardiovascular health rather than a short-term recovery programme. It calls for more personalised care, stronger

prevention, better referral pathways and greater policy support to help people manage cardiovascular risk throughout their lives.

For people living with inherited lipid conditions, the Roadmap reinforces the importance of early detection, timely treatment, long-term follow-up and patient-centred care. It also supports continued advocacy for healthcare systems that recognise prevention and lifelong cardiovascular management as essential parts of care, rather than optional extras. **Read more**

NEWS FROM AROUND THE WORLD

Sweden

First National Strategy for Rare Health Conditions

Sweden has adopted its **first National Strategy for Rare Health Conditions (2026–2030)**, marking an important step towards more coordinated, equitable and accessible care for the estimated **500,000 people living with a rare disease**. The strategy includes new funding to strengthen specialist care, knowledge, coordination and neonatal screening, while supporting Centres for Rare Diseases and patient organisations. It also reinforces collaboration between healthcare providers, researchers and the rare disease community to improve care and outcomes nationwide.

Austria

New National Lipid Consensus

Austria has published its new **Lipid Consensus 2026** (in German), a comprehensive, evidence-based guide for the prevention and treatment of lipid disorders across all ages. Led by **Prof. Florian Kronenberg**, the consensus provides practical recommendations tailored to the Austrian healthcare system, with a strong focus on prevention, early FH screening, and the management of inherited lipid disorders, including **FH, HoFH, FCS and elevated Lp(a)**. This important milestone strengthens cardiovascular prevention and lipid care in Austria.

KNOWLEDGE HUB

Expanding Treatment Options for High Cholesterol

Recent regulatory developments in the United States and Europe highlight continued progress in lipid-lowering therapies.

In **Europe**, the European Medicines Agency's (EMA) Committee for Medicinal Products for Human Use (CHMP) has recommended the approval of three new treatments: **lerodalcibep**, a once-monthly self-administered **PCSK9 inhibitor**, and **obicetrapib** and **obicetrapib/ezetimibe**, two once-daily oral **CETP inhibitor** therapies. The recommendations will now be reviewed by the European Commission before a final decision in 2-3 months. **Read more**

In the **United States**, the FDA has approved **enlicitide**, the first once-daily **oral PCSK9 inhibitor** for adults with high cholesterol, including people with heterozygous familial hypercholesterolaemia (HeFH). **Read more**

While these developments do not mean immediate patient access, they represent encouraging progress towards expanding treatment options and supporting more personalised care for people living with high cholesterol.

Continuing Education Opportunity: Patient Advocacy Academy

Through our ongoing collaboration with the **Healthcare Education Institute**, FHEF continues to highlight other training opportunities for patient advocates and organisation leaders working in **rare diseases**. The resources focus on helping patient organisations strengthen planning, develop strategic activities, and build practical advocacy skills through online learning, exercises, discussion circles, and peer exchange. We continue to share these training opportunities with Ambassadors and network members as part of our commitment to supporting stronger, more confident patient-led advocacy. **Find out more**

EPF Barometer: What It Means for Our Community

The **European Patients' Forum** has launched the **EPF Barometer**, a new initiative measuring how patient organisations are involved in health policy across Europe. Based on input from 27 national coalitions in 23 countries, it assesses patient involvement in areas such as decision-making, health technology assessment, transparency and healthcare system impact.

The findings highlight both progress and ongoing challenges, including limited resources and inconsistent opportunities for patient involvement. For our community, the Barometer reinforces the **importance of strengthening patient**

voices to improve awareness, early detection and access to care for inherited lipid disorders across Europe.

SAVE THE DATE

- **28-31 August:** **ESC Congress 2026**, European Society of Cardiology (ESC), Munich, Germany
- **15 September: Apheresis Awareness Day**
- **17 September:** **World Patient Safety Day**, World Health Organisation (WHO)
- **24 September:** **FH Awareness Day**
- **29 September:** **World Heart Day**, World Heart Federation
- **29 September - 4 October:** EU Screening Week
- **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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