
Welcome to the May 2026 edition of Heart Beat News



Heart Beat News

2 June 2026

May was a month of momentum for FH Europe Foundation and our community. From the World Heart Summit, the World Health Assembly, and EAS 2026 to major advances in research, advocacy, and patient engagement, we continued to strengthen the case for earlier detection and prevention of inherited lipid disorders. With the ongoing discussions on the future EU Council Recommendation on Cardiovascular Health Checks, now is the time to ensure that inherited lipid disorders remain firmly on the policy agenda.

FH EUROPE FOUNDATION NEWS

EU Advocacy update: Keeping up the momentum

May 19 was the deadline for the submission of the evidence to the European Commission public consultation on Cardiovascular Health Checks. We wish to recognise the international community that joined the effort to advocate for inherited lipid disorders and detection in the first decade of life. An incredible activation around the globe and involvement in a joint mission to prevent the preventable!

As discussions on the future EU Council Recommendation on Cardiovascular Health Checks continue, FH Europe Foundation is encouraging stakeholders to engage with national policymakers to support early screening for inherited lipid disorders. Advocacy materials, including a template letter, policy brief, supporting evidence, and national contact lists, are available to help strengthen these efforts.

[Access the email \(with advocacy assets\) sent to the network.](#)

FHEF response to EU call on cardiovascular health checks

FH Europe Foundation has submitted its response to the European Commission's Call for Evidence on Cardiovascular Health Checks, marking an important step for the inherited lipid disorders community. Strong mobilisation across patients, experts, and partners amplified the call for earlier detection and prevention. This collective effort supports recognition of FH, Lp(a), and FCS in future EU policy and aims to drive meaningful change across Europe.

[Learn more about it and read our submission.](#)



FHEF at the World Heart Summit

FH Europe Foundation participated in the 11th [World Heart Summit](#) in Geneva, bringing the voice of the inherited lipid disorders community to global discussions on cardiovascular health ahead of the [World Health Assembly](#). Represented by CEO **Magdalena Daccord** and Dr **Marina Leroy**, FHEF joined experts and policymakers in highlighting the importance of prevention, early detection, and equitable access to care.

A key highlight was the session *Making Lipid Control a Global Health Priority*, which reinforced the urgent need for stronger screening and management of dyslipidaemia and FH. Discussions also emphasised the importance of tackling misinformation, improving awareness, and turning existing evidence into effective policies and programmes. Throughout the Summit, a clear

message emerged: **prevention starts early, and patient-centred approaches must remain at the heart of cardiovascular care.**



FHEF at WHA79: Advancing global cholesterol action

FH Europe Foundation participated in several side events during the [79th World Health Assembly](#), contributing to discussions on cardiovascular prevention, integrated care, rare diseases, and health system transformation. Across all sessions, a common message emerged: **prevention and early detection must become central pillars of healthcare systems worldwide.**

A particular highlight was the discussion “*Lowering Cholesterol, Increasing the Impact: The Case for Earlier Action to Address the CV Epidemic*”, where Magdalena Daccord highlighted the growing political momentum for cardiovascular health in Europe, including the Council Conclusions on Cardiovascular Health and the EU Safe Hearts Plan. She emphasised the importance of strengthening awareness, early detection, and long-term action on inherited lipid disorders and cardiovascular risk, while ensuring that patients remain at the centre of policy and implementation efforts.

The discussions throughout the week reinforced that achieving better cardiovascular outcomes will require coordinated action across policy, healthcare, research, and patient communities, with prevention as the foundation of sustainable health systems.

EAS Paediatric FH symposium

FH Europe Foundation participated in the [9th EAS Paediatric Familial Hypercholesterolaemia Symposium](#), where international experts discussed the latest advances in the detection and management of FH in children. The discussions reinforced the importance of early identification, family-based screening, and timely treatment to prevent premature cardiovascular disease and improve lifelong health outcomes.



EAS 2026: Advancing science, policy and patient partnership

The [European Atherosclerosis Society \(EAS\) Congress](#) is one of the most important annual events for FHEF, bringing together the global scientific, clinical, policy, and patient communities working to improve cardiovascular health. For the third consecutive year, FHEF hosted a booth at the Congress in Athens, providing a vibrant space for discussion, networking, knowledge sharing, and strengthening collaboration between patients, healthcare professionals, researchers, and partners.

Throughout the Congress, discussions highlighted the growing momentum behind early detection and management of FH and elevated Lp(a), as well as the implementation of the EU Safe Hearts Plan. FHEF contributed to several key sessions, including the [Lp\(a\) International Task Force](#) session, where CEO **Magdalena Daccord** highlighted progress in securing recognition of FH and elevated Lp(a) within European cardiovascular health policy.

A particular highlight was the **recognition of Prof. Albert Wiegman**, FHEF Trustee and Chair of the Scientific Advisory Committee, as an EAS Honorary Member.

EAS 2026 also saw the publication of **two major consensus papers** relevant to our community, with more details available in the **Knowledge section** of this newsletter.

Lp(a) International Task Force meeting

Alongside EAS 2026, members of the [Lp\(a\) International Task Force](#) met in Athens to review progress and define priorities for the next phase of their work. Discussions highlighted major achievements, including the [Brussels International Declaration on Lp\(a\)](#), the inclusion of Lp(a) testing in the EU Safe Hearts Plan, and contributions to the forthcoming WHO Dyslipidaemias Guidelines. As momentum continues to grow globally, the focus is now shifting from awareness to implementation, with the goal of making Lp(a) testing and prevention part of routine cardiovascular care.



Upcoming HoFH Webinar Trilogy: Advancing Knowledge, Care, and Community

Following the momentum of HoFH Awareness Day and a period of significant progress in the field, we are launching a new webinar trilogy dedicated to HoFH. Bringing together leading experts, healthcare professionals, patients, and families, these sessions will explore key aspects of HoFH—from the importance of early diagnosis and screening to the latest treatment advances and the lived experiences of those affected by this rare condition. The series will also provide insights into the most recent scientific developments, including updates from the latest dyslipidaemia guidelines and newly approved therapies that are helping to reshape the future of HoFH care. As the treatment landscape continues to evolve, these webinars offer a valuable opportunity to better understand what these changes mean for patients, families, and healthcare systems.

Webinar 1: Starting Early: Changing the Future of HoFH

16 June 2026 | 5:00 PM CET

[Register here](#)

Webinar 2: New Frontiers in HoFH: Expanding Treatment Possibilities

23 June 2026 | 5:00 PM CET

[Register here](#)

Webinar 3: Living the HoFH Reality: Through the Lens of Children, Parents, and Siblings

30 June 2026 | 5:00 PM CET

[Register here](#)

Speaker line-ups are currently being finalised and will be announced shortly. We encourage all members of the community to save the dates and join us for these important conversations aimed at improving understanding, care, and support for people living with HoFH and their families.



Elsie Evans brings patient voice to EU Safe Hearts dialogue

FHEF Ambassador **Elsie Evans** participated in the discussion “*Gender Equity and Tobacco Control: High Impact Accelerators for the EU Safe Hearts’ Ambition*”, in Brussels, organised by [European Society of Cardiology](#) and the [Cyprus Presidency of the Council of the EU](#) 2026.

Sharing her lived experience with HoFH, she highlighted inequalities in care and the need for patient-centred policies. Her contribution reinforced the importance of addressing gender gaps, improving access to treatment, and ensuring cardiovascular prevention reflects real patient needs across Europe.



Young ambassador voice at Europe Biobank Week 2026

At [Europe Biobank Week 2026](#) in Prague, FHEF Ambassador **Lena-Rosa Hanauer** represented the patient voice in discussions on paediatric biobanking. Contributing to a workshop on patient involvement, she highlighted the need for trust, transparent communication, and meaningful youth engagement. Her input fostered dialogue between researchers and patients, reinforcing the value of collaboration to create more inclusive, patient-centred research systems.

Ambassador spotlight: Patsy on the Pioneering Patient Podcast

Our Ambassador **Patsy Petrie** shared her journey with heterozygous FH on *The Pioneering Patient Podcast*. After a 14-year path to diagnosis, she highlights the importance of early detection to prevent serious outcomes like heart attacks. The episode, produced with Global Heart Hub, underscores the value of patient voices in driving awareness, prevention, and better care for inherited lipid conditions. [Watch the full episode here.](#)



RESEARCH PROJECTS



perfecto
Preventing the Preventable

PERFECTO EU4Health Capacity Building Workshop on FH in Cyprus

As part of WP3 of [PERFECTO](#) project, the Capacity Building Workshop on FH was held in Cyprus, bringing together healthcare professionals, experts and mainly paediatricians to strengthen knowledge and collaboration around FH screening and prevention. The workshop featured an expert presentation by Prof. Albert Wiegman, trustee of FHEF, who shared insights on FH in children and adolescents and highlighted the importance of early detection and prevention. The programme also included a session on the Personalised Communication Model, delivered by Dr Andrie Panayiotou, focusing on how tailored communication approaches can support awareness, engagement, and patient-centred care. The event concluded with a panel discussion on collaborative approaches to FH screening and management across Europe.



PerMed FH



EAS
94th Congress
24-27 May 2026 | Athens, Greece



PerMed FH Consortium meeting in Athens

At the [PerMed FH](#) Consortium meeting in Athens, partners advanced work on genetic and lipid-related cardiovascular risk. Discussions focused on identifying new variants, strengthening precision medicine, and improving the safe clinical use of genetic data. The meeting reinforced collaboration across research and healthcare, supporting earlier diagnosis and better long-term management of FH. It marked another step toward more personalised, proactive cardiovascular prevention in Europe.



Survey for people living with FH: share your experience

[FH-EARLY](#) has launched a new survey inviting people living with FH to share their experiences of daily management, care, and support needs. Available in six languages (English, French, Czech, Portuguese, Turkish, Spanish), it aims to better understand real-life challenges and improve prevention, diagnosis, and cardiovascular care.

🕒 ~20 minutes | 🔒 Confidential

[Take part](#) or share with others.



NETWORK NEWS

China: FH China

HoFH patient treatment economic burden survey

In May, [Homy FH China Patient Network](#) conducted China's first survey on the economic burden of HoFH treatment. It gathered real-world data on costs, insurance, and affordability to support access to new therapies. Two versions (adult and caregiver) covered **five areas**, including finances and willingness to pay. Supported by strong outreach, **110 responses were collected nationwide in two weeks**. The results help fill a key data gap and strengthen reimbursement advocacy for innovative HoFH treatments.

Italy: AISC

Cardio-Renal-Metabolic risk prevention day in Rome

Following the great success of their first event, [AISC](#) announced a new prevention day dedicated to cardiovascular health. On June 18th, at Farmacia Roma Est in Rome, doctors and volunteers from the Italian Heart Failure Association (AISC) will provide free cardio-renal-metabolic risk assessments and, if necessary, laboratory testing. [Read more](#)

Sweden: FH Sweden

FH Sweden report marks 10 years of progress

[FH Sweden](#) has published a new report reviewing ten years of progress since the introduction of national FH guidelines. While all Swedish regions now offer structured FH care and diagnosis

rates have improved significantly, the report highlights that only around 15% of people living with FH have been identified. It calls for renewed efforts in early detection, paediatric screening, cascade screening, and primary care awareness to improve outcomes and reach more families affected by FH. [Read the report](#) (available in Swedish language).

Welcome to FH Iraq to the FHEF network

FHEF warmly welcomed FH Iraq as a new member of its network. Led by Dr. San Fatih, the organisation works to raise awareness, improve diagnosis, and support patients with FH and related lipid disorders. Collaborating with the Iraqi Lipid Clinics Network, FH Iraq promotes screening, education, and access to treatment. Their patient-centred approach and commitment to advocacy strengthen our shared mission to improve care and outcomes worldwide. [Read more](#).

PARTNER NEWS

EURORDIS

Upcoming EURORDIS mental health activities

[EURORDIS](#) continues to advance mental health and wellbeing in the rare disease community through several upcoming initiatives. These include a dedicated Mental Health Track at ECRD 2026 (4 June), a webinar presenting the results of the Rare Barometer survey on mental health and wellbeing (18 June), and a Mental Health Network meeting (9 July) to support the update of the EURORDIS Position Paper on Mental Health and Wellbeing.

More information and registration links:

- [ECRD 2026](#)
 - [Rare Barometer webinar](#)
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Health Technology Assessment International

HTAi Annual Meeting 2026

The Lp(a) International Taskforce (ITF) is proud to participate in the HTAi 2026 Annual Meeting in Istanbul, marking the first time the global Lp(a) community will engage directly with the international Health Technology Assessment (HTA) community on the opportunities and challenges of implementing Lp(a) testing in cardiovascular prevention. During the session, ***“System Shaping with Patients: Building Cost-Effectiveness Evidence for Lp(a) Screening with FH Europe Foundation,”*** Professor Zanfina Ademi, Professor Florian Kronenberg, Magdalena Daccord and Marc Rijken will be joined by Dr Iñaki Gutiérrez-Ibarluzea—Past President of HTAi, President of EuroScan, President of EUREGHA, to explore how scientific evidence can be translated into policy and real-world health system change in collaboration with patients and citizens. The discussion will highlight the growing recognition of Lp(a) as an important inherited cardiovascular risk factor, the momentum generated by the Brussels International Declaration on Lp(a), the landmark cost-effectiveness evidence supporting early testing in primary prevention, and the role of prevention, precision medicine, implementation science and health economics in shaping future cardiovascular health strategies. Importantly, the session will also showcase one of the defining strengths of the Lp(a) ITF: the meaningful involvement of patients and citizens as partners in research, policy development and implementation.

If you're attending HTAi, come and join the conversation Panel PN-15, HTAi 2026, Istanbul, Türkiye on 8 June 2026 at 17:45–18:45 local time. [Learn more](#)

NEWS FROM AROUND THE WORLD

Croatia

3rd “Run for Health” in Zagreb

The 3rd “Run for Health”, organised by the [Croatian Hypertension League](#) and [RunCroatia](#), brought together children and families in Zagreb to promote health literacy, physical activity, and prevention from an early age. Through *Hunt the Silent Killer*, the message was clear: health begins with education, movement, and childhood habits.

[Read more](#) and [watch the video](#)



UK

The Future for Rare campaign

Genetic Alliance UK's *Future for Rare* campaign highlights the urgent need to improve care for people living with rare conditions. For those affected by HoFH and FCS, it reflects shared challenges such as delayed diagnosis, limited access to specialist care, and barriers to treatment. The campaign calls for faster diagnosis, equitable care, and stronger patient voices, aligning closely with FHEF advocacy and the goal of better outcomes for all. [Learn more](#)

KNOWLEDGE HUB

Major step forward for cardiovascular prevention in Europe

Two landmark EAS consensus statements, announced and published last week during the EAS Congress in Athens, advance a shared vision for earlier and more effective cardiovascular prevention. One strengthens the **detection and management of FH in children, promoting earlier screening and treatment**. The other calls for **global harmonisation of lipid clinics to improve diagnosis, care, and access**. Together, they reinforce a life-course approach to prevention, support health system alignment, and highlight the importance of patient involvement in reducing the burden of cardiovascular disease. [Learn more](#)

EU webinar on youth engagement in cardiovascular prevention

The European Commission (DG SANTE) and the Slovenian National Institute of Public Health (NIJZ) will host a live webinar on **16 June 2026 (14:00–15:30 CEST)**: *“Beyond the Seat at the Table... Youth Engagement in NCD Prevention.”* Featuring interactive breakout sessions, it will co-create a Joint Statement to inform EU health policy.

[Read the invitation and register.](#)

REMEDI4ALL repurposing bootcamp for patient representatives (applications open)

Applications are now open for the REMEDI4ALL Bootcamp, a hands-on training on drug repurposing taking place in **Paris** on **2 to 3 November 2026**.

It is aimed at patient representatives in the **EU and UK** who want to deepen their knowledge, gain practical skills, and connect with others in the field. Travel expenses up to 300 EUR and accommodation are covered.

 [Apply here](#) by 10 June 2026

SAVE THE DATE

- 2-4 June: [PEOF 2026 Global Gathering](#), PFMD, Eupati, EPF, Sevilla, Spain
 - 3-4 June: [ECRD 2026 – European Conference on Rare Diseases & Orphan Products](#), Prague, Czechia & online
 - 5 June: [World Environment Day](#)
 - 8-10 June 2026: [HTAi 2026 Annual Meeting](#), Health Technology Assessment International, Istanbul, Türkiye
 - 28-31 August: [ESC Congress 2026](#), European Society of Cardiology (ESC), Munich, Germany
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