
Welcome to the April 2026 edition of Heart Beat News

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Heart Beat News

4 May 2026

The momentum continues to build across the FHEF community.

Following the strong success of the PERFECTO closing event highlighting the tangible progress achieved through collaboration, engagement around HoFH awareness has also gained remarkable traction. This growing visibility reinforces the collective commitment to improving recognition, diagnosis, and care for those affected.

Looking ahead, several key milestones are already on the horizon. Upcoming community calls will focus on the EU Health Checks Call for Evidence, offering an important opportunity to shape policy discussions. In parallel, the HoFH Trilogy webinar will deepen knowledge and exchange on this critical topic, while the EAS Annual Congress in Athens will provide a major platform for scientific dialogue and community presence.

Altogether, it's a particularly dynamic period for both the FHEF team and its wider network, marked by sustained engagement, strategic opportunities, and a shared drive to make meaningful impact.

FH EUROPE FOUNDATION NEWS



HoFH Awareness Day

As we mark [HoFH Awareness Day](#), we are reminded that the challenges faced by individuals living with Homozygous Familial Hypercholesterolaemia (HoFH) extend far beyond a single day of recognition. At FH Europe Foundation, we believe **this is not a one-day fight**. We remain committed to advocating year-round for the rights, early diagnosis, and equitable access to care for people living with HoFH and other inherited lipid conditions across Europe and beyond.

We would also like to warmly thank our community for their continued support and for widely sharing the assets from the [Awareness Day toolkit](#); your engagement is essential in amplifying this cause. Our work continues to elevate patient voices, support national advocacy efforts, and engage with policymakers and the medical community to drive meaningful change.

We are also pleased to share that a dedicated **webinar series** on HoFH is currently in development, with further details to be announced soon—**stay tuned**.



EU health checks Call for Evidence: act now for early detection of inherited lipid disorders

The European Commission has launched a critical [Call for Evidence](#) on cardiovascular health checks, an important opportunity to shape how early screening, detection and cardiovascular disease prevention are implemented across Europe. For our community, this is a key moment to ensure that inherited lipid disorders such as FH including HoFH, elevated Lp(a) and FCS are fully recognised and embedded in EU health policies. With millions still undiagnosed and at risk, coordinated action is essential. FHEF is preparing a unified response and invites you to engage strategically. **Join a community call on May 11th!**

- Option 1 at **12:30 CET** ([register here](#))
- Option 2 at **17:30 CET** ([register here](#))

More on our [website](#) and find out how to contribute before 19 May 2026.

Joint statement on Investing in Health: A Strategic Priority for Europe

Europe's leading cardiovascular and cancer organisations are calling on EU leaders to place health at the heart of future budget decisions. With nearly 3 million deaths each year and an economic burden of close to €500 billion annually, these diseases significantly impact both public health and Europe's productivity. The joint statement

emphasises that investing in prevention, care, and resilient health systems is not just a social necessity, but a driver of competitiveness and long-term growth. As discussions on the next EU budget continue, policymakers are urged to ensure dedicated and sustained funding for health. [Learn more](#)

ECO & EACH

Almost 3 million Europeans die every year due to cancer and cardiovascular disease

The economic burden is close to 500 billion euros, yearly.

The **current European Commission proposal** does not offer a clear budget for health

Support the Joint Statement

EAS Congress

FH Europe Foundation will be attending the [European Atherosclerosis Society \(EAS\) Congress](#) later this May in Athens (Greece). We are excited to be part of this key scientific and community gathering and to connect with colleagues, partners, and the wider cardiovascular community. Throughout the congress, FHEF will host a dedicated **booth** where participants are warmly invited to meet our **team** and connect with some of our inspiring **Patient Ambassadors**.

This will be a great opportunity to exchange insights, discuss ongoing initiatives, and learn more about our work advocating for individuals living with inherited lipid conditions across Europe and beyond. Stay tuned for more information about the session FHEF will be participating in—we look forward to sharing further details soon.

AMBASSADORS NEWS



PERFECTO – Ambassador training in-person

The 2nd PERFECTO Ambassador Training was held in Brussels on Sunday, 25 April. The session brought together **15 ambassadors, both in person and online**, for a focused and highly interactive strategic training. Building on previous trainings, the programme shifted towards practical application, equipping participants with the skills to translate scientific evidence and project insights into clear, impactful advocacy messages. Particular emphasis was placed on the **Personalised Communication Model (PCM)**, supporting Ambassadors in tailoring their messages to different audiences and policy contexts. Through discussions on the European policy landscape, including the Safe Hearts Plan, as well as exchanges with experts across the project, Ambassadors strengthened their ability to engage decision-makers and contribute actively to cardiovascular prevention efforts across Europe.



PERFECTO – Closing event

The PERFECTO closing event was enriched by the remarkable presence and contributions of our Ambassadors, whose voices brought a powerful human dimension to the discussions. During the panel *“Living with Familial Hypercholesterolaemia (FH) vs being a CVD patient: the Ambassadors’*

and clinicians' perspective", **Aija Grizāne** and **Athanasios Pallidis (Thanos)** shared compelling real-life experiences, contrasting early versus late diagnosis, and illustrating the profound impact of FH on daily life, treatment journeys, and long-term health outcomes. Their testimonies, alongside insights from clinicians, underscored the urgent need for improved detection and management strategies. The session was expertly guided by Magdalena Daccord, while the first day of the event benefited from the outstanding moderation of **Madalina Iamandei**, whose dynamic facilitation ensured engaging and meaningful exchanges throughout.

RESEARCH PROJECTS



PERFECTO closing event



The PERFECTO closing event marked a significant milestone and proved to be a great success, reflecting the strength and momentum of the initiative. With over **270 registrations from 69 countries**, the event brought together policymakers, clinicians, researchers, and patient advocates from across Europe and beyond, fostering rich and constructive discussions. Notably, the **FH EARLY** and **PerMed FH** consortium members were also present, highlighting the strong alignment across initiatives aiming to improve the diagnosis and management of FH patients.

We are currently reviewing the exchanges, including valuable inputs shared via the online chat, and will follow up on key points raised. A comprehensive **post-event report** is now in preparation, capturing the main messages and recommendations, which will feed into the upcoming **European Commission Call for Evidence on cardiovascular diseases – health checks.**

In parallel, a dedicated publication on the **Social Return on Investment (SROI)** of the PERFECTO approach is being developed under the leadership of our partner **EuroScan.**

NETWORK NEWS

HoFH Awareness Day 2026

May 4 2026



1. Light Up Avatar movement
2. Patient stories
3. Social media Q&A challenge
4. Light Up the Map of HoFH
5. Diagnosis and Treatment Brief
6. International joint communication

China: FH China

Six Actions for HoFH Awareness Day

FH China led a comprehensive six-part campaign in April to raise awareness for HoFH Awareness Day. Key actions included the “*Light Up Avatar*” movement to create visual impact, sharing authentic patient stories, and the “*Light Up the Map*” initiative to highlight patient distribution. A **social media Q&A challenge** launches on May 4, alongside the release of the **2026 China HoFH Diagnosis and Treatment Brief** to support policy change, while global collaboration amplifies Chinese patient voices.

Czechia: ČAKO

Bringing Preventive Health Screenings to Key National Institutions

ČAKO organised **two high-profile health days** in April at the **Senate of the Parliament of the Czech Republic and Prague Castle**. Their team provided cholesterol, blood sugar, and blood pressure checks, along with personalised consultations. **Over 200 people were screened** across 16 hours of education, with two probable FH cases identified. ČAKO continues these awareness and prevention activities year-round.

[Watch the video](#) from the Senate of the Parliament of the Czech Republic, capturing the work of the medical staff.

Italy: AISC

AISC Invites Patients to Join BIOTOOL-CHF Survey

AISC is supporting the [BIOTOOL-CHF European research project](#) on chronic heart failure by promoting a **patient survey**. The initiative aims to improve care through biomarkers, digital tools, and AI. The survey gathers insights on daily life, healthcare experiences, and quality of life, helping ensure patient perspectives shape future research and treatment strategies. The insights collected will help refine the design of the clinical study and ensure that patient perspectives are meaningfully integrated into the research.

Access the survey [here](#).

Netherlands: Stichting VrouwenHart

Stichting VrouwenHart contributes to European EXIT-CVD project

Stichting VrouwenHart is proud to contribute to **EXIT-CVD**, a European project that aims not only to better understand cardiovascular disease, but to change its trajectory. Together with **42 organisations from 17 countries**, EXIT-CVD will identify “exit points” where disease progression can be slowed, stopped or reversed, helping earlier detection and better treatment truly land in clinical practice. They contribute to the patient’s perspective, with a strong focus on women’s experiences and gender differences in cardiovascular care. [Learn more](#)

Spain: Familial Hypercholesterolaemia Foundation

XI FH Symposium Videos Now Available Online

Familial Hypercholesterolaemia Foundation Spain has published the videos from its **XI Symposium, “Data Value in Personalized Medicine,”** held in Madrid on 12–13 March 2026. This annual meeting, dedicated to healthcare professionals, focuses on reducing cardiovascular disease in inherited lipid disorders. The recordings also highlight insights from the long-running SAFEHEART study, offering valuable real-world evidence to the community. Watch the videos [here](#).

NEWS FROM AROUND THE WORLD



Croatia

First-ever comprehensive cardiovascular screenings in the European Parliament: Croatian prevention model in focus

On April 8, 2026, the European Parliament hosted the “Know Your Numbers: Cardiovascular Health Check Zone” initiative, led by **MEP Romana Jerković**. For the first time, comprehensive

cardio-renal-vascular screenings were conducted on this scale within the Parliament. Based on Croatia's "Hunting the Silent Killer" model, the initiative provided 70 participants with immediate results and personalised advice, highlighting the importance of early detection and prevention.

Read the full report: [CHL in European parliament](#).

France

The power of advocacy




We warmly welcome the important update shared by our network member [Anhet.f](#). After years of dedicated advocacy, a major milestone has been reached: a new bill championed by **Yannick Neuder** has **successfully passed the National Assembly and is now moving to the Senate**. Among several key measures to strengthen cardiovascular health and disease prevention, the legislation introduces **systematic screening for familial hypercholesterolaemia in children from the age of six**. This represents a crucial breakthrough, particularly in France, where an estimated 30,000 children are affected by FH. This achievement highlights the impact of sustained advocacy, strong collaboration, and political leadership in advancing public health, and we now look ahead with optimism to the next stage in the Senate.

KNOWLEDGE HUB

EAS AtheroTalk episode with Magdalena Daccord

Magdalena Daccord, CEO of the FH Europe Foundation, is featured in Episode 30 of the **AtheroTalk podcast**, produced by the European Atherosclerosis Society. In this insightful discussion, she explores key challenges and future directions in the management of FH, highlighting the importance of patient advocacy, early diagnosis, and cross-border collaboration. She also underscores the impact of global initiatives such as the [Lp\(a\) International Task Force](#), as well as the crucial role of patient networks in raising awareness and improving access to care for individuals living with inherited lipid disorders—fully aligned with our mission to ensure that every patient is identified, supported, and empowered, wherever they are.

Listen to the podcast on

-  Spotify: <https://zurl.co/kMHgu>
 -  Apple Podcasts: <https://zurl.co/lfUft>
 -  YouTube: <https://zurl.co/sm1OY>
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European Patients' Rights Day 2026 – 20th edition

The 20th edition of European Patients' Rights Day 2026 will take place on 12 May 2026 from 14:00 to 16:00 CEST at the European Parliament in Brussel. This year's event will focus on **personalised prevention**, promoting a shift away from one-size-fits-all approaches toward strategies that reflect individual risk, needs, and lived experience. This is particularly relevant for

the FH community, where early identification, targeted prevention, responsible use of health data, and strong patient involvement are key to improving outcomes and reducing inequalities in care. The event will bring together EU institutions, researchers, patient organisations, and other stakeholders to explore how empowered citizens can help shape the future of prevention in Europe, and participation is still open upon [registration](#) for online attendance.

SAVE THE DATE

- 4 May: [HoFH Awareness Day](#), FHEF
 - 4-8 May: [European Mental Health Week](#), Mental Health Europe
 - 16-17 May: [World Heart Summit](#), WHF
 - 18-23 May: [World Health Assembly \(WHA79\)](#), WHO
 - 19-22 May: [Europe Biobank Week Congress](#), BBMRI-ERIC
 - 23 May: [9th EAS Paediatric Familial Hypercholesterolaemia Symposium](#), EAS
 - 24-27 May: [94th EAS Congress](#), EAS
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