Welcome to FH Europe Foundation’s April 2025 edition of Heart Beat.

FH Europe Foundation April 2025 Heart Beat Newsletter

Welcome to the April FH Europe Newsletter.

As spring continues to unfold, we’re pleased to share recent highlights and upcoming priorities from across the FH Europe Foundation network. This month included timely awareness moments, such as Patient Rights Day and today’s World DNA Day—both reinforcing our shared commitment to patient-centred care, genetic literacy, and equitable access to healthcare.

Looking ahead, our focus turns to HoFH Awareness Day. We’re preparing to launch a dedicated Webinar Trilogy exploring the challenges of diagnosis, treatment, and policy—an important step in strengthening visibility and support for those living with HoFH. In parallel, we’ll also host Public Advocacy webinars in collaboration with EACH, diving into the Council Conclusions and the European Cardiovascular Health Plan.

This edition reflects on the successful Ambassador Programme training and the PERFECTO FH Consortium meeting in Cyprus and shares key takeaways from the Lp(a) Global Summit as we begin shaping the Brussels International Declaration.

You'll also find the latest network and partner updates, impactful patient stories, 3 new publications covering topics of genetic testing and FH management, and a preview of upcoming events such as the EAS Congress and the World Heart Summit. In the Knowledge Hub, don't miss the upcoming webinars on all important Council Conclusions which, for the first time, talk about FH, elevated Lp(A) and rare diseases as well as women's herat health, and finally the EU HTA Regulation webinar —an important opportunity for ambassadors and advocates across the network.

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FH EUROPE FOUNDATION NEWS

"Galaxy Forces United" for HoFH Awareness Day 2025

On Sunday, **May the 4th**, we mark the second **HoFH Awareness Day**. The 2025 HoFH Awareness Day campaign, "**Galaxy Forces United: For HoFH Awareness Day**", seeks to unite people living with HoFH, their families, healthcare professionals, researchers, and advocates in the space of this rare and severe form of FH to raise awareness of Homozygous Familial Hypercholesterolaemia (HoFH), a rare and life-threatening genetic condition.

May will be the dedicated month for awareness activities, education, and community engagement.

A central feature of this year’s campaign is the educational webinar series, **"HoFH 360° – A New Hope for Every Generation"**, launching in May 2025. This trilogy will explore the HoFH journey across different life stages, offering expert insights, patient experiences, and live audience Q&A sessions.

We are proud to share that the campaign toolkit will be available in 18 languages. The efforts to raise awareness are supported by the International Atherosclerosis Society, Global Heart Hub and the Iraqi Lipid Clinics Network, with more partners to come in the next days, making it a truly global initiative.

Visit the HoFH Awareness Day webpage to get involved! Download the HoFH Awareness Toolkit and share your own post on social media using #Unite4HoFH and tag FH Europe Foundation.

Read more about HoFH Awareness Day and Download the Toolkit **here**.


INVITATION

Introduction of the Lp(a) International Taskforce

Monday, 5. 5. 2025, 10:30-11:00 GMT
Room: EAS Stage in the Exhibition

Chair:

Introduction of the International Lp(a) Taskforce and its mission

A patient journey to avoid: the perspective of a person with lived experience

Is Lp(a) testing cost-effective in the primary CVD prevention?

Call to action - the Brussels International Declaration on elevated Lp(a)

FH Europe Foundation at EAS Congress 2025 – See You in Glasgow!

FHEF will be taking part in the European Atherosclerosis Society (EAS) Annual Congress 2025, happening from May 4–7 in Glasgow, Scotland. As one of the world’s leading scientific events focused on atherosclerosis and lipid research, the EAS Congress is the place where the latest science, innovation, and advocacy come together — and we are proud to continue building on our long-standing collaboration with the Society. Although the UK’s compliance rules limit some of the the possibilities in which patients can participate in this event, FHEF is planning a strong and vibrant presence.

This year’s Congress coincides with the HoFH Awareness Day, on May 4th. We look forward to using this opportunity to engage the scientific and clinical community in raising awareness about Homozygous Familial Hypercholesterolaemia (HoFH). On May 5th, we will hold a session on elevated Lp(a), presenting the work of the Lp(a) International Taskforce and the publication of the Brussels International Declaration. The declaration comes as a result of the first global Lp(a) Global Summit and the breakthrough study on cost-effectiveness of Lp(a) testing.

Read more about our presence **here**.

FH Europe Foundation Supports the Launch of the MEP CVH Group

On April 23, FH Europe Foundation’s Magdalena Daccord and Nicola Bedlington joined the EU policymakers, experts, and patient advocates at the European Parliament in Brussels for the inaugural meeting of the Members of the European Parliament (MEP) Cardiovascular Health Group. The event was hosted by MEP Romana Jerković (Croatia), Chair of the Group, and supported by several committed MEPs. During the event, the European Alliance for Cardiovascular Health (EACH) launched its new publication: **A European Cardiovascular Health Plan: The Roadmap**. The Plan builds on the first EACH policy document ‘A European Cardiovascular Health Plan: The Need and the Ambition’ which contributed to the prioritisation of CVH in Europe, written by Nicola Bedlington. The high-level meeting served as a great opportunity to promote PERFECTO FH with some of the MEPs, as well as share about the upcoming HoFH Awareness Day and the work in the area of elevated Lp(a) with the upcoming publication of the Brussels International Declaration.

Read more about it in the PARTNERS section below.

Meeting with MEP Jerkovic – follow up from the Lp(a) Global Summit

Following the launch event of the **MEP Cardiovascular Health Group**, a positive and productive meeting was held with **MEP Romana Jerković** at her office in Brussels. The meeting provided an excellent opportunity for Magdalena Daccord and Nicola Bedlington to follow up on the outcomes of the **Lp(a) Global Summit** and to discuss the next steps for the **Brussels International Declaration on Lp(a) Testing and Management**. We were delighted that MEP Jerković accepted the invitation to join the upcoming **FHEF Annual Network Meeting in Zagreb, Croatia**, and seemed to be very happy about becoming part of the **FH Europe Foundation Ambassadors Community**. Ideas to host a dedicated event at the European Parliament were also on the agenda. We are deeply grateful to MEP Jerković for her ongoing support for cardiovascular health in Europe and her commitment to advancing CVD prevention, particularly in the area of **inherited lipid disorders.**

First In-Person Ambassadors' Training: A Milestone for the Advocacy Community

From April 10–11, the FH Europe Foundation hosted its first-ever in-person Ambassador Programme training in Limassol, Cyprus, as part of the PERFECTO FH project. The event was held under the auspices of the Cyprus Ministry of Health and gathered 35 enthusiastic participants from 14 countries, including patients and caregivers representing the full spectrum of lipid disorders supported by FHEF.

Over two intensive days, attendees deepened their understanding of familial hyperlipidaemias, advocacy, and policymaking, with a particular focus on paediatric FH screening as a case study. Participants had the opportunity to hear from a representative of the Cypriot Ministry of Health and learn from leading experts—researchers, healthcare professionals, patient organisation leaders, and policy advisors from across Europe.

The training agenda was packed with essential topics, covering the science of FH, various screening models and management strategies, and the European health policy landscape. Sessions also addressed personalised communication techniques and the psychological impact of living with FH. However, what truly left a lasting impression were the interactive workshops and role-playing exercises, where participants practiced engaging with Members of the European Parliament and national policymakers.

The significance of the event was further amplified by national media coverage, with a feature aired on Cyprus's national television highlighting the importance of FH awareness, early screening, and cardiovascular disease prevention.

The training concluded with a proud moment for all participants, who received certificates of completion. The programme was officially recognised by the Cyprus University of Technology with continuous learning credits, marking an important step forward in professional and patient advocacy development within the FHEF community.

Read more about it **here**.

PERFECTO FH consortium partners meeting

The PERFECTO FH consortium partners held a successful in-person meeting in Limassol, Cyprus on 8 April 2025, ahead of the Ambassador Training Programme. The gathering provided an excellent opportunity to assess the progress of ongoing work, debrief on outcomes from the European Preventive Cardiology Congress, where early results on the personalised communication model were presented (WP3), and to plan the preparation of upcoming deliverables (WP2). Discussions also focused on the design of the final consortium event, which the partners aspire to host under the upcoming Cypriot Presidency of the Council of the European Union. As part of the project's deliverables, the Ambassador Training was hosted by the consortium, culminating in a high-level in-person meeting at the Cypriot Ministry of Health in Nicosia on 15 April 2025, where future strategies for familial hypercholesterolaemia (FH) screening combined with elevated Lp(a) testing in the context of the national CVH Plan were discussed with national health authorities.

World DNA Day: Unlocking the Power of Genes in Inherited Lipid Conditions

April 25 marked World DNA Day – a global celebration of genetic science and innovation. This year's theme, "Unlocking the Power of Gene," highlights how genetics is shaping the future of healthcare, particularly for individuals with inherited lipid conditions such as familial hypercholesterolaemia (FH), familial chylomicronaemia syndrome (FCS), homozygous familial hypercholesterolaemia (HoFH), heterozygous FH (HeFH), and elevated lipoprotein(a) [Lp(a)].

At FH Europe Foundation, we are committed to advancing genetic understanding and personalised care. Through projects such as PerMed FH (tailoring treatment through genetic insights), FH EARLY (improving early diagnosis and co-management of FH) and PERFECTO FH (promoting personalised prevention though paediatric FH screening), we are helping build a healthier future.

Read more about it here.

Marking European Patients' Rights Day

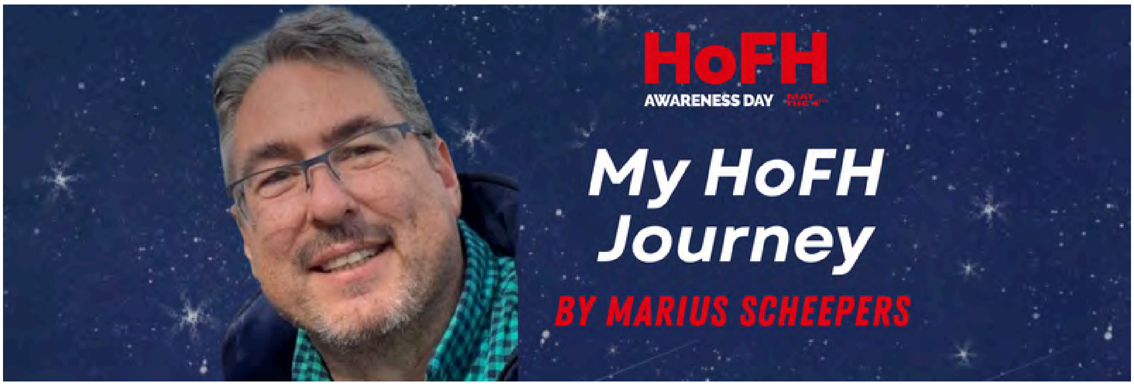
On April 18, European Patients' Rights Day was celebrated across the continent – a meaningful occasion to raise awareness about patients' rights and promote their protection in all healthcare systems. Established by Cittadinanzattiva/Active Citizenship Network, this annual day is rooted in the European Charter of Patients' Rights, which sets out 14 fundamental rights to ensure equitable, respectful and person-centred care.

FH Europe Foundation we proudly support the initiative all year round, advocating for the rights of people living with inherited lipid conditions (HeFH, HoFH, elevated Lp(a), and FCS). We believe that every person deserves timely diagnosis, access to treatment, and the opportunity to be actively involved in decisions about their care.

This year, FHEF invited members of the community to reflect on what these rights meant in their daily lives. Six FHEF patient ambassadors shared personal insights into the rights that resonated most with them, bringing the Charter to life through powerful stories and lived experiences. These testimonials are a reminder that rights-based care is not merely a principle – it is a reality we must all strive to uphold and advance.

Read more about it and hear from FHEF patient ambassadors here.

PATIENT
STORY



Marius' Journey with HoFH

Marius Scheepers, from South Africa, was diagnosed with Homozygous Familial Hypercholesterolaemia (HoFH) at just two years old, after his mother noticed unusual yellow growths on his heels. What followed was a lifetime of treatments, drug trials, hospital stays, and resilience. Despite losing his father at nine and undergoing major heart surgeries—including a triple bypass and valve replacement—Marius remained determined to live fully. From cricket games and a career in management to raising twins with his supportive wife, his story is one of strength and hope. Now 51, Marius lives in the UK and continues to advocate for awareness, calling himself a "beacon of LIFE." He believes in the power of science and is confident that a cure is on the horizon.

Read more about it here.

NETWORK
NEWS

Greece - LDL Greece

Raising Awareness about HoFH in Greece

On May the 4th, HoFH Awareness Day, LDL Greece will host together with Rare Diseases Greece an awareness event dedicated to Homozygous Familial Hypercholesterolaemia (HoFH) at the Municipality of Soufli in the Evros region. The event aims to educate the public and healthcare professionals on the importance of early diagnosis and proper management of FH and HoFH.

The one-hour programme will include talks from a cardiologist, a primary care physician, and Thanos Pallidis, representative of LDL Greece, who will share his personal experiences. Thanos is an HoFH patient Ambassador, who will highlight the role of FH Europe Foundation in supporting patients across Europe.

This collaborative effort will spotlight the daily challenges of living with HoFH, the power of patient advocacy, and the importance of being part of a strong European network.

Ireland - Croí

‘Her Final Search’ Campaign Sheds Light on Heart Attack Symptoms in Women

Croí and Global Heart Hub have launched the ‘Her Final Search’ campaign to raise awareness about the unique symptoms of heart attack in women. Inspired by real-life stories, the campaign highlights signs often overlooked, such as jaw, neck, and back pain. A recent survey found that only half of Irish women knew symptoms could differ from men's, with less than 1% accurately identifying them. Through emotional videos shared on social media, the campaign encourages women to trust their instincts and seek help promptly. It aims to reduce delays in diagnosis and save lives by improving symptom recognition.

Read more about it and watch the videos **here**.

New Community Stroke Hub Opens at Croí Heart & Stroke Centre

Croí has officially opened the Joe & Helen O’Toole Community Stroke Hub at the Croí Heart & Stroke Centre in Galway, marking a major step forward for stroke recovery services in the West of Ireland. Thanks to the generosity of the Joe & Helen O’Toole Charitable Trust, the new facility offers essential rehabilitation programmes, therapies, and carer support. As the first hub of its kind in the region, it strengthens Croí’s commitment to stroke prevention, cardiovascular care, and disease management. The centre now welcomes stroke survivors, families, and carers seeking specialised support and rehabilitation.

Read more about it **here**.

Poland - EcoSerce

Heart Disease in Focus at Health Advocates 2025: EcoSerce’s Contribution

EcoSerce took part in the Health Advocates 2025 congress, held on 1–2 April in Warsaw, where heart disease was a key topic. Experts, including Agnieszka Wołczenko, President of the National Eco Heart Association, discussed progress like the KOS ZAWAŁ programme but also highlighted areas needing improvement. Prof. Robert Gil emphasised the need to shift from hospital-centred care to a stronger role for primary care. Wołczenko stressed that stabilised patients could be managed by family doctors, easing specialist queues. The National Cardiology Network and Electronic Coordinated Care Card (EKOK) were presented as solutions to streamline care. Speakers also called for better access to drug treatments and more public-private partnerships.

Read more about it **here**.

Singapore - FHCARE Singapore

FH Connect 2025: Understanding Familial Hypercholesterolemia Together

On May 24, 2025, FH Care Singapore, in collaboration with healthcare partners, will host FH Connect 2025 at Admiralty Medical Centre. This free event is designed for individuals and families living with Familial Hypercholesterolaemia (FH).

The programme features expert talks on the basics of FH and LDL cholesterol, the importance of genetic testing and inheritance, available medications, and cascade screening, including the use of innovative tools like chatbots. A panel discussion and Q&A session will address the key concerns of FH patients and explore ideas for future community activities.

Date: Saturday, May 24, 2025
Time: 9:30 AM – 1:00 PM
Venue: Room 3, Level 4, Admiralty Medical Centre, Kampung Admiralty, Singapore

Registration: Register **here** (free of charge)

FHEF is proudly supporting this event and invites you to come learn, connect, and build a supportive FH community together!

Read more about it **here**.

Global Heart Hub

GHH Grow: Navigating Social Media Changes

Global Heart Hub invites you to its next Grow training, Adapting to a Changing Social Media Landscape, on Tuesday, May 13. Led by social media expert Paul Sutton, the session will explore recent shifts in platforms, declining organic reach, and how patient organisations can adapt and stay connected. It includes a one-hour presentation followed by optional small group discussions, with Zoom providing translated captions in 35+ languages.

Register **here**.

NEWS
FROM AROUND THE WORLD

Cyprus

Cyprus Establishes Patients Advocate Office

The House of Representatives has passed legislation creating the Office of the Patients' Advocate, a new mechanism to receive and address complaints from patients. Two bills were approved—one establishing the advocate's office, the other abolishing the Gesy Commissioner, with powers now divided between the Patients' Advocate and the Ministry of Health. Although the advocate will operate independently, the appointment will be political, made by the President. Reporting to the office will be rights officers based in hospitals and healthcare facilities, alongside new district-level patients' rights committees. The advocate will oversee healthcare services both within and outside Gesy, meeting a long-standing call from patients' rights groups.

Read more about it here.

PARTNER NEWS

The European Alliance for Cardiovascular Health - EACH

European Alliance for Cardiovascular Health (EACH) Unveils Roadmap at EU Parliament

On April 23, 2025, the European Parliament in Brussels hosted the inaugural meeting of the MEP Cardiovascular Health Group, chaired by MEP Romana Jerković. The event marked a major milestone for the European Alliance for Cardiovascular Health (EACH) with the launch of its flagship publication: A European Cardiovascular Health Plan: The Roadmap

The Plan, cocreated by the EACH partners, outlines an ambitious goal: to reduce premature and preventable deaths from cardiovascular disease (CVD) by one third by 2030. Built around five pillars—prevention, early intervention, rehabilitation, quality of life, and equity—it calls for action at every level of the healthcare system. Proposed initiatives include a European Cardiovascular Health Check, a CVH Knowledge Centre, and a Health Observatory, backed by digital innovation and national action plans.

With over 60 million people affected and CVD still the leading cause of death in Europe, this roadmap represents a powerful call for unified, cross-border action.

Download the publication here.

European Atherosclerosis Society - EAS

EAS Congress 2025: Advancing Research in Atherosclerosis

The 93rd Congress of the European Atherosclerosis Society (EAS) will take place on 4–7 May 2025 in Glasgow. The event, organised together with the British Atherosclerosis Society, will offer in-person and virtual participation. Experts will explore the latest in basic, translational, and clinical research on atherosclerosis and vascular disease, with sessions featuring keynote lectures, workshops, and the prestigious Anitschkow Lecture. Members of the FH Europe Foundation will also attend, contributing to discussions and strengthening collaborations in the field.

🆓 ***Good news for our community!*** There are 5 free online registrations available for members of the FHEF Community (patients and patient ambassadors). Don’t miss the opportunity to be part of this important event! If you are interested in one of the complimentary online registrations, please contact **elsie@fheurope.org**.

Read more about it **here**.

European Patients’ Forum - EPF

Civil Society Urges Stronger EU Health Union

On March 26, EPF joined the EU4Health Civil Society Alliance event in the European Parliament on integrating health into the next EU budget. Hosted by four MEPs, the discussion stressed making health a priority in the upcoming Multiannual Financial Framework (MFF). Panellists, including EPF’s Anca Toma, highlighted the need for sustainable funding, stronger emergency preparedness, and support for civil society. A joint statement released earlier in March raised concerns over future EU4Health funding. Public consultation on the MFF is open until May 7.

Read more about it **here**.

Upcoming Webinar on Patients’ Rights in the European Health Data Space

Following the recent entry into force of the European Health Data Space (EHDS) regulation in March 2025, the European Patients’ Forum (EPF) is organising a webinar to help patients and stakeholders understand the impact of this major development.

The event, "Understanding patients’ rights in the European Health Data Space", will take place on May 15, 2025, from 11:00 to 12:00 CET. It will explore how the EHDS empowers citizens with better access to and control over their health data, and the role of patient organisations in ensuring its effective implementation. The session will also highlight the importance of health data literacy to help individuals make the most of their new rights.

Read more about it and register here.

World Heart Federation—WHF

10th World Heart Summit: Driving Action for Global Cardiovascular Health

The 10th World Heart Summit will take place on May 17-18, 2025, in Geneva, ahead of the 78th World Health Assembly. Leaders from government, business, civil society, and academia will gather to tackle key challenges in cardiovascular health, from strengthening primary care to advancing innovations in treatment. Hosted at the Biotech Campus, the Summit will focus on turning science into policy and action to shape a healthier future. Set in the heart of global health diplomacy, the event promises critical discussions and collaborations for lasting impact.

Read more about it here.

NEW PUBLICATIONS

New Publication Highlights Barriers and Facilitators to Genetic Testing for FH

We are pleased to share the publication of a new systematic review, "**Facilitators and Barriers to Uptake of Genetic and Cascade Testing in Familial Hypercholesterolaemia**," in the *International Journal of Behavioural Medicine*. This important work, a collaboration between researchers in Singapore and several of our FH Europe Foundation Patient Ambassadors, strengthens the growing body of behavioural science research supporting FHEF's advocacy efforts.

The review examines why the uptake of genetic testing (GT) and cascade testing (CT) for Familial Hypercholesterolaemia (FH) remains low, despite their proven role in preventing premature cardiovascular events. Analysing 15 qualitative and quantitative studies covering over 270,000 respondents, the findings show that beyond simple awareness, personal perceptions — especially the perceived value of testing — strongly influence decision-making. Key facilitators identified include family history of illness, strong healthcare provider support, and personal responsibility towards family health. On the other hand, emotional distress, family disconnect, financial concerns, and a perceived lack of benefit were major barriers.

The authors call for future interventions that not only increase knowledge but also improve communication strategies, address emotional and systemic barriers, and create culturally sensitive approaches to support a more patient-centred decision-making process around GT and CT for FH.

The full article is available open-access **here**.

Early Use of Ezetimibe After a Heart Attack Helps Prevent Future Heart Problems: New Study Findings from Sweden

A new study from the SWEDEHEART registry, published in the *Journal of the American College of Cardiology*, shows that starting a combination of cholesterol-lowering medicines — statins plus ezetimibe — soon after a heart attack can protect patients from future serious heart problems.

Lowering LDL cholesterol ("bad" cholesterol) after a heart attack is very important to prevent future heart attacks, strokes, or deaths. While high-dose statins are commonly used, fewer than 1 in 5 patients reach their recommended cholesterol targets with statins alone. Although guidelines suggest adding other medications like ezetimibe if needed, they often recommend doing so step-by-step, only after seeing if statins alone are enough. This study looked at whether starting ezetimibe early — instead of waiting — could make a difference.

Researchers studied over 35,000 people in Sweden who had a heart attack between 2015 and 2022. They compared three groups: those who started ezetimibe within 12 weeks of leaving hospital (early combination therapy), those who started it later (up to 16 months after), and those who never added ezetimibe. The results were clear: patients who started ezetimibe early had fewer heart attacks, strokes, and deaths than those who started late or not at all. After three years, patients who delayed adding ezetimibe or never added it had significantly higher risks of serious cardiovascular events.

The findings strongly suggest that heart attack patients should be given combination therapy with statins and ezetimibe early as part of standard care. Waiting to add ezetimibe or relying only on statins could lead to avoidable health risks.

The full study is available **here**.

New IAS Guidance: Turning FH Best Practices into Action

We are excited to share the new publication, **"Implementation Strategies for Improving the Care of Familial Hypercholesterolaemia**," published in the *American Journal of Preventive Cardiology* and now available open access. This collaboration between FH Europe Foundation and the International Atherosclerosis Society (IAS) responds to global calls for action on FH.

While previous guidelines explained what to do for FH care, this new IAS guidance focuses on how to make it happen. Using an implementation science approach, experts developed 80 practical recommendations covering screening, diagnosis, family cascade testing, treatment across all ages, pregnancy care, and advanced therapies like apheresis. These strategies aim to help healthcare professionals, policymakers, and patient organisations adapt best practices to their local settings and improve outcomes for people with FH.

The authors emphasise the urgent need for localised plans, supportive health policies, sustainable funding, and broader use of implementation science to bring high-quality FH care to families worldwide.

Read the full article **here**.

KNOWLEDGE HUB

Shaping the Future of Cardiovascular Health in Europe- Exclusive Webinar Series on EU Council Conclussions!

FH Europe Foundation, on behalf of the European Cardiovascular Health Alliance (EACH), is launching a special series of public advocacy webinars to empower patients, advocates, and the wider community. Hear directly from the person who led the efforts, Ms Kitti Amler, the Hungarian Public Health Attaché, joined by representatives of EACH. Learn how the new EU Council Conclusions and the forthcoming European Cardiovascular Health Plan can drive better prevention, care, and research for cardiovascular diseases. Discover how you can engage policymakers, influence national health strategies, and turn policy into action. Featuring top EU health experts, policymakers, and patient voices, these dynamic sessions will give you the knowledge and tools to be part of Europe's next major health transformation. Don't miss this opportunity to be heard – and to shape the future of cardiovascular health across Europe!

Register now:

- Option 1 - **May 30**: **Register here**.
- Option 2 - **June 16**: **Register here**.

EU Health Technology Assessment (HTA) Regulation webinar for more patient-centred health policies

FH Europe Foundation invites its Ambassadors and community members to attend a crucial webinar on the new EU Health Technology Assessment (HTA) Regulation. This session will explain how patients, carers, and clinical experts can participate in joint clinical assessments and consultations, helping shape more patient-centred health policies.

The webinar, hosted by the HTA Coordination Group and Secretariat, will also demonstrate the use of the new HTA IT Platform for submitting inputs and declarations of interest.

Date: Friday, May 16, 2025
Time: 12:30–14:30

Register here for the webinar **here**.

SAVE THE DATE

- **May 3** – EAS FH Paediatric Symposium 2025
- **May 4** – HoFH Awareness Day
- **May 4-7** – 93rd EAS Congress
- **May 17-18** – World Heart Summit, Switzerland
- **November 14-16** – FH Europe Foundation Annual Meeting, Croatia

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