FH Europe Foundation’s May&June 2025 edition of Heart Beat.

FH Europe Foundation May & June 2025 Heart Beat Newsletter

As summer sets in, we’re excited to share a special double edition of our newsletter, reflecting the energy and achievements of the past two months across the FH Europe Foundation network and beyond.

We continued the momentum of HoFH Awareness Day 2025 with a dedicated webinar trilogy and launched our international logo competition—both designed to raise visibility and inspire community engagement.

In advocacy, we marked the publication of the Brussels International Declaration on Lp(a), the adoption of the Rare Disease Resolution at the World Health Assembly, and wrapped up the webinars on EU Council Conclusions on CVD.

FH Europe Foundation and Ambassadors took part in major events across the region, from EAS in Glasgow, EURORDIS Annual Meeting in Riga, and the World Heart Summit followed by the World Health Assembly in Geneva to an atherosclerosis congress in Helsinki, a global patients' Advisory Board meeting in Florence, and a high level event on inherited lipid disorders in Brussels, where we joined international leaders to discuss how to tackle high cholesterol.

We're also proud to share updates from our Network: LDL Greece hosted an inspiring HoFH awareness event, and FHchol Austria delivered two impactful educational sessions. Plus, don't miss news and resources from our partners, including EAS, EPF, EURORDIS, WHF, and Global Heart Hub, and more. Enjoy the read and have a great start to summer!

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FH EUROPE FOUNDATION NEWS

Continuing the Celebration of HoFH Awareness Day

On May 4th, we proudly celebrated HoFH Awareness Day 2025—shining a light on Homozygous Familial Hypercholesterolaemia and its impact on individuals and families worldwide. But our work didn't end there. Throughout May and early June, we continued raising awareness and fostering understanding of this rare and serious condition through a series of initiatives.

Now Available: HoFH 360° Webinar Trilogy Recordings

In this three-part series, we explored the journey of living with HoFH, from early diagnosis and family planning (*The Inherited Legacy*), through the challenges of transitioning from paediatric to adult care (*The Teenage Rebellion*), to managing life as an adult with HoFH (*The Future Strikes Back*). Each session featured expert insights, real-life stories, and engaging discussion.

Whether you missed the live events or want to revisit the discussions, all episodes are now available to watch on demand.

Watch all episodes **here**.

Call for Entries – Design the 2025 HoFH Awareness Day Logo

We are launching a global **logo competition** to create the official symbol for **HoFH Awareness Day 2025**. Whether you're a designer, artist, or creative enthusiast, we invite you to help visualise this year's theme:
"Galaxy Forces United: For HoFH Awareness Day"

The winning design will be used in international campaigns and receive special recognition from the FH Europe Foundation.

Let your creativity inspire global awareness. Submit your design and be part of the movement.

Read more about it **here**.

Brussels International Declaration on Lp(a) Officially Published

A milestone for heart health: the Brussels International Declaration on Lp(a) Testing and Management has been published in *Atherosclerosis* and announced at the EAS Congress 2025 in Glasgow. Developed by the Lp(a) International Task Force, led by FH Europe Foundation and Prof. Florian Kronenberg, the Declaration urges global action on elevated Lp(a)—a major, underdiagnosed cardiovascular risk. It outlines five key policy asks, from routine testing to public awareness. The Declaration is now open for endorsement by individuals, organisations, and governments.

Even more remarkably, it was accompanied by a powerful Editorial by Professors Jan Borén, M. John Chapman, and Chris Packard. Rarely does such strong scientific consensus intersect so clearly with public health urgency and political opportunity. The publication is open access, ensuring that all stakeholders, regardless of geography or resource, can benefit from this evidence-based tool.

Endorse it now, **here**.
Read more about it **here**.

Public Advocacy Webinars: EU Action on Cardiovascular Health

In May and June 2025, FH Europe Foundation, on behalf of the European Alliance for Cardiovascular Health (EACH), hosted two editions of a public advocacy webinar to explain the EU Council Conclusions on Cardiovascular Health, adopted in December 2024. These Conclusions mark the first EU-wide political commitment to cardiovascular health in over 20 years.

The webinars featured expert speakers including Kitti Almer, Public Health Attaché of Hungary to the EU and Chair of the drafting group behind the Conclusions, as well as representatives from the European Society of Cardiology and Global Heart Hub. They addressed the urgent need to tackle CVD, the leading cause of death in Europe, and unpacked the Conclusions' five key pillars—prevention, early detection, treatment, rehabilitation, and innovation, while highlighting the critical role of civil society in turning policy into action.

With 126 participants from 34 countries, 73% reported feeling more informed and empowered to advocate for cardiovascular health across Europe. The full text of the Council Conclusions can be accessed at the **official EU document portal**.

If you missed the webinars and would like to **watch the recording**, please visit **FH Europe Foundation´s YouTube Channel**.

Read more about it **here**.

Help Secure EU Funding for Cardiovascular Health

The development of the **EU Cardiovascular Health Plan (EU CVH Plan)** is accelerating — and your support is needed now more than ever.
Thanks to years of advocacy, the EU has committed to a dedicated CVH Plan. But to make it a reality, **multi-year funding must be secured in the upcoming EU budget**. The European Commission’s proposal is expected as early as July, making the next few weeks critical.

What you can do:

1. **Contact your national Minister of Finance** using our template letter.
2. **Let us know once you’ve acted** — your feedback strengthens our collective voice.

📥 Need help with your outreach? Contact us at info@fheurope.org.

Read the full briefing and access resources **here**.
Let’s turn policy into progress — together.

A historic milestone for the global rare disease community: The Resolution on Rare Diseases - adopted!

We’re excited to share a historic achievement: the **Resolution on Rare Diseases** was officially adopted at the **78th World Health Assembly (WHA78)**!

This global milestone marks a significant step forward in advancing **equity, visibility, and inclusion** for the 300 million people worldwide living with rare diseases. FH Europe Foundation is honoured to have been a **supporter and coalition member**, standing alongside **Rare Diseases International** and 275 civil society organisations in pushing for this breakthrough.

FHEF has been a **dedicated and engaged member of the coalition led by Rare Diseases International**, working tirelessly to help bring this resolution to life. We extend our sincere thanks to the **WHO Member States**, especially **Egypt and Spain**, who championed this initiative on the global stage.

This is **wonderful news for individuals and families affected by rare diseases**, including those in our own community living with **Familial Chylomicronaemia Syndrome (FCS)** and **Homozygous Familial Hypercholesterolaemia (HoFH)**. It represents a tremendous opportunity to improve awareness, access to care, and quality of life.

Congratulations to all who contributed to this historic moment. Let’s continue working together to turn this global commitment into meaningful action at the national and regional levels.

Learn more about the Resolution **here**.

FH Europe Foundation at the EURORDIS Membership Meeting in Riga

FH Europe Foundation joined rare disease advocates in Riga at the EURORDIS Membership Meeting 2025. The team took part in key sessions, including Data in Action: Rare Barometer findings and an advocacy workshop, and connected with partners such as the Latvian Alliance of Rare Diseases and Aiga Balode, Latvia’s Deputy State Secretary for Digitalisation.

The event offered a valuable opportunity for message-testing, skill-building, and advancing a shared purpose within the European rare disease community.

Read more about it **here**.

International Patient Voices Unite in Florence on Cholesterol and CVD

FH Europe Foundation took part in a Global Advisory Board in Florence, co-hosted with MENARINI Group, uniting patient leaders and individuals with lived experience to address high cholesterol and cardiovascular disease.

The group explored conditions like FH and HoFH, tackled stigma and awareness gaps, and highlighted the need for broader access to lipid-lowering therapies. Key advocacy milestones—including the CVH Plan for Europe—were also celebrated.

The meeting reinforced the value of patient voices in shaping care, policy, and education across Europe.

FH Europe Foundation at the SATY Conference in Helsinki

FH Europe Foundation was honoured to join the 18th Annual Conference of the Finnish Atherosclerosis Society (SATY) in Helsinki. CEO Magdalena Daccord shared how the Foundation translates science into policy by placing lived experience at the centre.

Highlights included sessions on FH genetics, elevated Lp(a), and triglycerides, with contributions from EU projects like FH-EARLY and PerMed FH.
The Foundation secured 21 new endorsements of the **Brussels Declaration on Lp(a)** and a pledge of support from SATY, following a powerfull keynote presentation by Prof. Florain Kronenberg, Chair of the Lp(a) Inernational Taskforce.

A heartfelt thank-you to the organisers for an impactful and forward-looking event.

FHEF Ambassadors to Champion Lived Experience at the 2025 Global Forum on Value in Health

We are delighted to announce that **FH Europe Foundation is an official partner** of the **2025 Global Forum – Taking the Value Conversation Forward in Health**, taking place on **4–5 December in Glasgow**. Co-hosted by Sprink and the Scottish Government, this landmark event brings together international leaders to explore how we can create real value in health through prevention, personalisation, technology, and strategic collaboration. FH Europe will be proudly represented on stage by two of our Ambassadors: **Helga Davidson**, living with **Familial Chylomicronemia Syndrome (FCS)**, and **Madalina Iamandei**, living with **Familial Hypercholesterolemia (FH)**, who will share their lived experience and advocate for more person-centred, value-based care in rare diseases.

The Forum promises to be **practical and forward-looking**, highlighting real-world examples of value-based prevention, innovative uses of AI in care delivery, and tools to expand person-centred healthcare at scale. With a focus on **what truly matters to individuals**, the event aims to move beyond theory and deliver actionable strategies that will shape the future of equitable and sustainable healthcare.

Join us in Glasgow this December to be part of this transformative event. Let's work together to turn lived experience into lasting impact and help build a healthcare system that truly delivers value for all. FHEF Network Members and Ambassadors can enjoy a special discount.

For full details on the programme, speakers, and how to register, please visit the Forum website.

Living with Inherited Lipid Disorders — At the Heart of MEP Sokol's Event

Last week, **FH Europe Foundation (FHEF)** proudly took part in a milestone event at the **European Parliament**, hosted by **MEP Tomislav Sokol**, placing the spotlight firmly on **familial hypercholesterolaemia (FH)** and **elevated lipoprotein(a) [Lp(a)]** in the context of the forthcoming **EU Cardiovascular Health Plan**.

Patient Ambassador Marie-Therese O'Donohue delivered a powerful first public address, sharing her lived experience with high Lp(a) and calling for urgent policy action to improve detection, education, and care. **Magdalena Daccord**, FHEF CEO, presented the Foundation's key achievements — including the **EU recognition of FH paediatric screening** — and introduced the **Prague and Brussels Declarations** as vital frameworks for advancing early detection across Europe.

The event featured high-level institutional voices, including **Mr. Csaba Kántor**, leading the development of the EU CVH Plan, and **Ms. Ewa Piasecka**, **Health Attaché of Poland**, who shared promising national strategies on FH and Lp(a) screening. Scientific experts **Prof. Michal Vrablík** and **Prof. Ivan Pećin** contributed compelling clinical evidence and implementation examples from **Czechia** and **Croatia**, respectively.

Closing remarks were delivered by Prof. Davor Miličić, Croatian Academy of Sciences and Arts, who emphasised the importance of cross-border collaboration and early detection in combating cardiovascular disease.

The event was **co-sponsored by Novartis**, whose support helped elevate the visibility and urgency of integrating inherited lipid disorders into EU-level cardiovascular strategies.

This event marked a clear turning point — recognising these conditions not as peripheral, but as **central to the EU's cardiovascular agenda**. **FHEF is proud to be at the forefront of this shift**, ensuring lived experience continues to drive policy that saves lives.

FH Europe Foundation to Partner with the World Orphan Drug Congress 2025

We are thrilled to announce that the **FH Europe Foundation (FHEF)** will **officially partner** with the **World Orphan Drug Congress 2025**, the world's largest and most established event focused on orphan drugs and rare diseases. Taking place from **27 to 29 October 2025** at the **RAI Congress Centre in Amsterdam**, this global gathering brings together leaders from science, government, industry, and patient advocacy to drive meaningful progress across the entire orphan drug value chain — from cell and gene therapy to genetic testing, market access, and real-world evidence.

We are proud to be part of this important event dedicated to rare diseases, where we will be speaking on stage, sharing our work and experiences in the rare lipids space (HoFH and FCS), and hosting a small booth to connect with attendees and partners from around the world. As part of our involvement, we are inviting our **Ambassadors** to join us on-site by applying to volunteer at the booth and attending the Congress. This is a fantastic opportunity to be part of the rare disease community's most impactful annual event, support our mission, and represent FH Europe on the international stage.

We look forward to seeing many of you in Amsterdam as we work together to advance rare disease advocacy and policy.

For more information and to apply as a volunteer, please contact **info@fheurope.org**.
Visit the official event homepage.

PATIENT
STORY

Elias: Living with FH, Parenting Through HoFH

In our HoFH 360° Webinar Trilogy’s first episode, The Inherited Legacy – Family Planning & Caring for Children with HoFH, one of the speakers was Luke Elias from Australia, who shared a deeply personal story of discovery, resilience, and hope.

At 30, Luke was fit, active, and a new dad. A routine check-up revealed high cholesterol, which he managed with lifestyle changes and medication, without knowing it was familial hypercholesterolaemia (FH). Years later, a small grey ring in his young son’s eye led to a shocking diagnosis: both of his sons had homozygous FH (HoFH), a much more severe and rare genetic condition. This prompted further testing and the realisation that both Luke and his wife were FH carriers.

In the webinar, Luke reflects on the emotional journey of parenting through uncertainty, the importance of family intuition, and what he wishes he had known earlier. His story is a powerful reminder that you are not alone—and that support, knowledge, and connection can change everything.

We warmly invite you to hear Luke's full story and explore the insights shared in this impactful episode. Don't miss the chance to listen to the webinar and learn from the experiences of families living with HoFH.

Watch the webinar recording **here**.

NETWORK
NEWS

Austria - FHchol Austria

Understanding FCS: Online Meeting with Experts

On June 24, FHchol Austria hosted an informative online session dedicated to Familial Chylomicronaemia Syndrome (FCS) for participants from Austria, Germany, and Switzerland. The meeting featured two expert speakers:

- **Gabriele Skacel**, dietitian at Vienna's AKH Children's Hospital, shared valuable insights on nutrition for people living with FCS.
- **Thomas Stulnig**, discussed symptoms, diagnostic approaches, and available therapy options.

Held in German, the session created space for participants to ask questions, exchange experiences, and deepen their understanding of FCS. The patients were also invited to attend an FCS cooking course, which will be held in early November in Vienna. Details for the cooking course will follow in due time.

Personalised Cholesterol Therapy: FHchol Austria Online Regulars' Table

On June 3, FHchol Austria organised an engaging online "Stammtisch" focused on personalised cholesterol therapy.

Marcus Täuber from the Austrian company Permedio introduced the concept of tailoring treatment based on genetic analysis, highlighting how drug compatibility and effectiveness can vary from person to person.

The session, conducted in German, offered participants practical knowledge and a chance to explore the future of personalised care in lipid management.

World Congress on Clinical Lipidology in Vienna

The World Congress on Clinical Lipidology in Vienna brought together experts from Europe, the United States, and Australia. FHchol Austria played an active role by offering free Lp(a) tests on Saturday, 28 June, which were warmly welcomed by attendees. Lena Rosa Hannauer, a young FHchol member and FHEF patient ambassador, took blood samples from one of our FHchol members, while the remaining tests were conducted by medical professionals.

Greece - LDL Greece

LDL Greece Hosts HoFH Awareness Event in Soufli

LDL Greece organised an awareness event titled *“Herein Cholesterol and the Power of Prevention”* at the Silk Art Museum in Soufli. The event honoured HoFH Awareness Day, aiming to raise visibility of this rare condition, highlight the patient journey from diagnosis to treatment, and promote broader understanding of familial hypercholesterolaemia.

The evening featured talks from two physicians who explained FH and its forms in simple, relatable terms. Dr. Georgios Papagoras focused on diagnosis, treatment, and the importance of psychological well-being, while Dr. Alexandros Vasiliou spoke from a primary care perspective, emphasising prevention, lifestyle, and long-term management.

Vice President of LDL Greece, Thanos Pallidis, shared his personal experience of living with HoFH and spoke about the critical role of patient associations and the impact of FH Europe at the European level. The event closed with an open Q&A session and the symbolic lighting of the museum in the colours of LDL Greece.

Singapore – FHCARE Singapore

FH Connect 2025: A Meaningful Gathering for the FH Community

On May 24, 2025, FH Connect 2025 brought together individuals and families affected by Familial Hypercholesterolaemia (FH) at Admiralty Medical Centre in Singapore. The event provided a valuable morning of education and connection. Participants had the opportunity to hear from leading medical experts, learn about genetic testing and available treatment options, explore digital tools for managing FH, and take part in a panel discussion focused on real-life challenges and future support strategies.

Among the speakers were Associate Professor Subramaniam Tavintharan, Dr Natalie Koh, Professor Fabian Yap, Dr Fathima Ashna, Dr Sanjaya Dissanayake, Dr Loh Wann Jia, and Dr Sharon Pek.

FH Connect 2025 highlighted the importance of cascade screening, given that FH often remains undetected within families. The FHCare team is proud to have taken this step forward in raising awareness and remains committed to partnering with the community to improve care and support for all those living with FH.

Global Heart Hub

Global Heart Hub Launches 2025 Heart Failure Awareness Campaign

Global Heart Hub has launched its 2025 Heart Failure Awareness Campaign: "**Heart Failure and Connected Conditions – *The Whole Story.***" The campaign aims to raise awareness of heart failure and its links to conditions like diabetes, kidney disease, obesity, and high blood pressure. Running from May to December and available in 16 languages, it promotes early detection, coordinated care, and improved outcomes. As part of the campaign, a patient-centred webinar with Diabetes Initiative Indonesia will take place on 21 May.

Read more about it **here**.

Unite for Change: A Call to Transform Cardiovascular Care for People Living with Multiple Conditions Worldwide

Global Heart Hub has launched its transformative *Unite for Change: Transforming Cardiovascular Care for People Living with Multiple Conditions* report, a policy roadmap built on five key joint asks for integrated, equitable and people-centred care, advocating to drive change and transform cardiovascular care for people living with Multiple Interconnected Chronic Conditions (MICC). The report presents a clear policy roadmap built on **Five Key Joint Asks**, shaped by people with lived experience and supported by global health leaders:

1. **Multidisciplinary Care & Navigation**
2. **Early Detection & Community Screening**
3. **Innovation & Digital Health Access**
4. **Equity in Care**
5. **Prevention, Empowerment & Mental Health Integration**

Global Heart Hub is calling on all healthcare stakeholders to take immediate action to embed these reforms into national and international health strategies Read the report **here**.

NEWS
FROM AROUND THE WORLD

European Institute of Women's Health

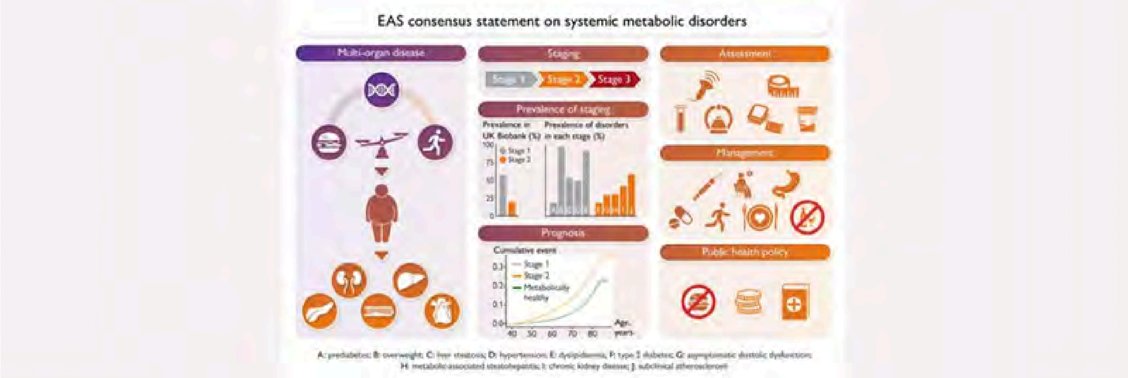
Launch of the EIWH EU Women's Health Strategy

On June 24, 2025, the European Institute of Women's Health (EIWH) officially **launched the EU Women's Health Strategy**—a major milestone for gender-sensitive healthcare in Europe.

Based on the **2024 Women's Health Manifesto** and supported by nearly 50 organisations, the strategy outlines a comprehensive roadmap to improve women's health through inclusive, evidence-based EU policy.

The online event brought together key stakeholders and advocates to discuss the strategy's priorities and implementation.

PARTNER
NEWS



European Atherosclerosis Society - EAS

New EAS Consensus Statement on Metabolic Disorders and Cardiovascular Risk

The European Atherosclerosis Society (EAS) has published a new consensus statement titled *Clinical staging to guide management of metabolic disorders and their sequelae*, featured in the *European Heart Journal* (May 2025). This publication provides a structured approach to the early identification and treatment of metabolic diseases, aiming to reduce the burden of related conditions such as cardiovascular disease, type 2 diabetes, and fatty liver disease.

Developed by an international panel of experts, the statement is part of the ongoing EAS Consensus Position Paper Initiative, which plays a key role in shaping clinical guidance on lipid disorders and atherosclerosis. The initiative is coordinated by leading researchers and clinicians across Europe and beyond.

This new staging model has potential implications for improving long-term outcomes in individuals with inherited lipid conditions, including familial hypercholesterolaemia (FH), by supporting more timely and personalised interventions.

Read more about it **here**.

European Patients' Forum - EPF

MEPs Back EU4Health CSA Call for Sustainable Civil Society Support

The EU4Health Civil Society Alliance (EU4Health CSA) has received strong support from leading EU Public Health MEPs for its open letter to European Commission President Ursula von der Leyen. The letter urges swift adoption of the 2025 EU4Health Work Plan and the continuation of operating grants for health NGOs.

Seven MEPs from across political groups have endorsed the call, highlighting the risk to public health efforts if civil society organisations are left without funding. The Alliance warns that delays threaten key health priorities, from cancer and NCDs to mental health and health equity.

The EU4Health CSA represents over 30 health NGOs working for a stronger European Health Union.

Read more about it **here**.

Call for Patient Representatives: PROACT EU-Response Project

The European Patients' Forum is inviting applications to join the Patient Advisory Group (PAG) for the PROACT EU-Response project, which aims to improve Europe's preparedness for future pandemics. Up to 15 patient representatives will provide input on trial design, patient materials, and engagement strategies.

Applicants must be 18+, based in Europe, with advocacy experience and knowledge of clinical trials or pandemic preparedness. Priority is given to those with experience in infectious respiratory diseases, but all interested patient advocates are welcome.

Read more about it here**.**

Patients Call for Stronger Involvement in EU Medicines Regulation

The European Patients' Forum (EPF), alongside EURORDIS, is calling on EU policymakers to protect **patient voting rights** within EMA committees as part of the upcoming pharmaceutical legislation.

In a joint statement, now supported by over 70 patient organisations, the two groups express concern that recent Council proposals risk weakening patient involvement in the CHMP and PRAC.

As trilogue negotiations began on 17 June, EPF urges decision-makers to ensure patients remain equal partners in shaping Europe's medicines policy.

Read more about it here.

EURORDIS

Maximising impact at EMM 2025 in Riga

This May, rare disease advocates from across Europe gathered in Riga for the EURORDIS Membership Meeting 2025. With workshops on political advocacy, EMA engagement, HTA, ERNs, and data from Rare Barometer, the event focused on equipping participants to strengthen their voice and impact. Representing FH Europe Foundation were Elsie Evans, Ambassador Programme Manager, and Maja Bartoszewicz-Moritz, Rare Disease Project Manager, who spoke on the importance of data in inclusive policy-making. The meeting reaffirmed the need for united, well-informed advocacy to shape a better future for people living with rare diseases across Europe.

Read more about it **here**.

Rare Diseases Must Be Central to EU Life Sciences Strategy

As the European Commission prepares to unveil its Life Sciences Strategy, EURORDIS urges policymakers to prioritise rare diseases as a key test case for innovation, equity, and resilience. With 30 million people in Europe affected and 95% of rare diseases lacking treatment, the strategy must include targeted investment, regulatory reform, and equitable access measures. Rare disease research drives major medical advances and strengthens Europe’s scientific leadership. EURORDIS outlines clear policy actions to ensure no one is left behind.

Read more about it **here**.

Safeguarding Patient Voices at the EMA

On 12 June, EURORDIS and the European Patients’ Forum (EPF) launched the **#KeepPatientsVoting** campaign, urging EU lawmakers to protect patient representatives’ voting rights in two key EMA committees: CHMP and PRAC.

The campaign responds to the Council of the EU’s stance on new pharmaceutical legislation, which removes voting rights in CHMP and cuts patient seats in PRAC—undermining earlier proposals by the Commission and Parliament. Now backed by 70+ patient groups, the campaign provides advocacy tools ahead of trilogue talks starting 17 June.

This is part of EURORDIS’ broader push to strengthen patient roles and support innovation in rare disease treatments.

Read the **Joint Statement from EPF and EURORDIS** or the **full press release**.

European Society of Cardiology - ESC

ESC Congress 2025: Cardiology Beyond Borders

The ESC Congress 2025 will take place in Madrid and online from 29 August to 1 September, marking the 75th anniversary of the European Society of Cardiology. Held with the World Congress of Cardiology, this year’s theme, *“Cardiology Beyond Borders,”* will highlight global health challenges, equity, innovation, and patient perspectives.

Key updates include new ESC Guidelines, Hot Line trial results, and dedicated tracks on AI, cardiometabolic health, and the patient voice.

Read more about it **here**.

World Heart Federation—WHF

Obesity Stigma Undermines Cardiovascular Health

The World Heart Federation warns that stigma and gaps in care are putting millions at risk of cardiovascular disease (CVD) due to rising obesity. In its *World Heart Report 2025*, launched at the World Heart Summit, the organisation highlights how bias, poor access to treatment, and aggressive marketing of unhealthy foods are fuelling the global crisis. Obesity-related CVD deaths have more than doubled since 1990, with the greatest impact now seen in middle-income countries. The report urges governments to address stigma, ensure access to treatment, and implement policies that promote heart-healthy environments.
Read more about it **here**.

NEW
PUBLICATIONS

Alcohol Increases Cardiovascular Risk

The European Heart Network has published a new position paper on alcohol and cardiovascular disease. It challenges the belief that moderate drinking is heart-healthy, showing no protective effect and identifying alcohol as a risk factor for heart disease, stroke, and hypertension. In the EU, alcohol contributes to over 50,000 cardiovascular deaths annually and imposes a €125 billion burden on healthcare systems. EHN urges stronger policies, including labelling, pricing, availability, and marketing restrictions.

Read the full paper and view the infographics **here**.

What blood fats reveal about women’s heart health

Heart disease is still the leading cause of death in women—and an often-overlooked risk factor is the role of blood fats like cholesterol, triglycerides, and

Lp(a). A new review, featured by *VrouwenHart*, explains how these values shift throughout a woman’s life, especially during menopause. Hormonal changes, particularly the drop in estrogen, can worsen lipid profiles and increase cardiovascular risk. The article calls for earlier testing, more attention to Lp(a), and a stronger focus on gender-specific prevention and care.

Read more about it Dutch **here**.
Read the publication **here**.

KNOWLEDGE
HUB

Understanding the European Health Data Space (EHDS)

Feedback from FH Europe Foundation ambassadors following EPF training

The European Patients’ Forum (EPF) has launched a **new toolkit** to explain the European Health Data Space (EHDS), a major EU initiative aiming to improve how health data is accessed and used across Europe. The initiative is part of Data Saves Lives.

Several FH Europe Foundation ambassadors attended EPF’s recent training session on EHDS. We thank Renate Kaal-Poppelars for compiling their key insights.

The EHDS is designed to ensure that all EU citizens can securely access their health data, wherever they are in the EU, and to allow this data to be used for better care, research, and health policy. It introduces two main types of data use:

- Primary use for direct care (e.g. prescriptions, test results), where patients remain in control
- Secondary use for research and innovation, with strict privacy protections and the right to opt out
- National authorities will oversee how data is accessed and shared, with full compliance under GDPR. The EHDS will be implemented gradually, starting in 2025, with full rollout planned by 2035.

For the FH Europe Foundation community—especially those affected by familial hypercholesterolaemia (FH) and other inherited lipid conditions—the EHDS offers real potential: earlier diagnosis, improved continuity of care across borders, and stronger support for research into rare and underdiagnosed diseases.

Patient organisations are encouraged to raise awareness, support members in understanding their rights, and contribute to shaping a system that works for all.

Read more about it **here**.
More information is also available on the **Data Saves Lives website**.

SAVE THE DATE

- **August 29 - September 1** - European Society of Cardiology Congress 2025
- **September 16** - World Apheresis Day
- **September 17** - World Patient Safety Day
- **September 24** - FH Awareness Day
- **September 29** - World Heart Day
- **October 27 - 29** – World Orphan Drug Congress Europe 2025, Amsterdam, Netherlands
- **November 1** - FCS Awareness Day
- **November 14-16** – FH Europe Foundation Annual Meeting, Zagreb, Croatia
- **December 5 - 6** – 2025 Global Forum, Glasgow, Scotland

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