
Welcome to FH Europe Foundation’s October 2024 edition of Heart Beat.

FH Europe Foundation October 2024 Heart Beat Newsletter

Welcome to the October edition of our Heart Beat Newsletter!

As we embrace the vibrant month of October, we are gearing up for two significant events: FCS Awareness Day on November 1 and our Annual Network Meeting from November 8 to 10. It's been a bustling month for us as we travelled around the globe to advocate for cardiovascular health (CVH) and familial lipid disorders. Our team has proudly represented FH Europe Foundation at the World Health Summit in Berlin, Asia-Pacific Heart Summit in Bangkok, the World Orphan Drug Congress in Barcelona, and the EP PerMed Symposium on Personalised Medicine in Brussels. We've also celebrated the 25th Anniversary of the Portuguese FH Study and attended the CV Prevention & Intervention Conference in Warsaw. Additionally, our patient ambassadors participated in SOLFED’s 10th Medical Day online from Lyon, sharing their invaluable insights.

In this edition, you'll find exciting updates from our network members in Austria, France, Ireland, Spain, and the UK, along with news from our partners and a new publication from the FHSC team. Don't miss the upcoming events that we have in store for you!

Wishing you an enjoyable read and a fantastic weekend ahead!

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FH EUROPE FOUNDATION NEWS

FCS Awareness Day

This Friday, November 1, join the international community to raise awareness for Familial Chylomicronaemia Syndrome (FCS), a rare and serious lipid disorder that prevents the body from breaking down fat. People with FCS often experience intense abdominal pain, fatigue, and life-threatening pancreatitis, making daily life a constant balancing act around food.

We’re thrilled to share that, for the first time, global FCS patient groups—Action FCS (UK), the Asociación Síndrome Quilomicronemia Familiar (Spain), the FCS Foundation (USA), and FH Europe Foundation—are joining forces to amplify the voices of FCS patients, families, and advocates.

Help raise awareness by trying the #FCS10gFatChallenge, an everyday reality for those with FCS who must limit their fat intake to manage symptoms. On Awareness Day, try limiting yourself to just 10g of fat—a small step to experience the unique challenges of those with FCS.

The FCS diet also means that ‘good fats’ are also off limits. So, no avocado, nuts, seeds, or olive oil. For example, half a small avocado contains 15g fat, so that is over the maximum limit for the day!

Want to participate? Share your experience and tag #FCS10gFatChallenge to inspire others to join in!

Learn more on the websites:

Action FCS

Asociación Síndrome Quilomicronemia Familiar

FCS Foundation

FH Europe Foundation Annual Meeting in Vienna

The FH Europe Annual Network Meeting is just around the corner, taking place next weekend in Vienna! We’re thrilled to bring together a diverse community of more than 120 participants from 37 countries, including expert speakers, patient ambassadors, and leaders in advocacy, under the theme “Together, Engaged for Change.”

The programme features carefully curated sessions on key topics in lipid health, patient advocacy, and precision medicine. International experts and ambassadors will lead insightful discussions, debates, and workshops aimed at creating a lasting impact on awareness, treatment, and support for patients.

Ahead of the main event, we’ll premiere a special four-part webinar series on HeFH, HoFH, FCS, and elevated Lp(a), designed to enhance health literacy and awareness around these inherited lipid conditions. Stay tuned for webinar dates and updates!

Read more about it **here**.

Advancing Cardiovascular Health: Insights from the World Health Summit in Berlin

Magdalena Daccord, CEO and Nicola Bedlington, Senior Policy Advisor, represented the FH Europe Foundation at the World Health Summit in Berlin. Magdalena presented at a World Heart Federation-hosted side session about "Policy Pathways to Prevent, Detect, and Manage Cardiovascular Disease in Low- and Middle-Income Settings." This conversation, which emphasised the significance of supporting national CVD/CVH action plans, was pertinent as Europe gets ready for the CVH Action Plan.

In order to address the issue of cardiovascular disease (CVD), the WHF side event presented a forum for multistakeholder discussion, displaying a variety of viewpoints, challenges, and prospects. The realisation that a one-size-fits-all strategy is insufficient was an important lesson learnt from the discussions. Panelists agreed that there is a common sense of urgency and resolve to tackle CVD.

Asia-Pacific Heart Summit

We were thrilled to participate in the **Asia-Pacific Heart Summit** organised by the Asia-Pacific Cardiovascular Disease Alliance in Bangkok. Emma Print, our Community Engagement Manager, attended the summit, engaging in significant conversations including the importance of early detection, seamless treatment, and community empowerment in the management of cardiovascular disease (CVD). On day three FH Europe Foundation was invited to participate in the patient round table, co-hosted by our partner, Global Heart Hub. Connecting with other patient organisations in our Network including Croí Heart & Stroke Charity, Parsirdi.lv from Latvia and FH Singapore, we highlighted the need for cohesive national CVD strategies and inclusive, equitable care for all. This event demonstrated how crucial awareness-raising events like World Heart Day and FH Awareness Day are to advancing the global conversation on cardiovascular health issues.

World Orphan Drug Congress Europe 2024

We are excited to announce that FH Europe Foundation attended the World Orphan Drug Congress Europe in Barcelona last week! Representing our community will Elsie Evans, our Ambassador Programme Manager, and a person living with a rare condition represented our community.

Our focus is on advocating for better health outcomes for those affected by two rare familial lipid disorders: Homozygous Familial Hypercholesterolaemia (HoFH) and Familial Chylomicronaemia Syndrome (FCS). This year, we launched the first-ever HoFH Awareness Day on May 4th, and we're currently promoting the #FCS10gFatChallenge as we approach FCS Awareness Day.

FH Europe at the EP PerMed Symposium on Personalised Medicine

On September 26, 2024, FH Europe Foundation's CEO, Magdalena Daccord, proudly represented the foundation at the EP PerMed Symposium on Ethical, Legal, and Social Aspects of Personalised Medicine in Brussels. The event explored the differences between precision and personalised medicine, ethical considerations, and the importance of advocacy. Expert presentations and thought-provoking discussions highlighted citizen engagement and public outreach strategies.

Magdalena also participated in the first EP PerMed Citizen Engagement Board meeting, discussing key strategies for public engagement. The event offered valuable networking opportunities with European Commission representatives, researchers, and medical professionals.

Also, the first episode of their new podcast series 'The Science of You' is out! This podcast series will explore the groundbreaking discoveries that are allowing us, through **Personalised Medicine**, to understand and harness these differences, transforming the way we approach medicine and healthcare.

DNA is the blueprint of life. In the first episode, the team trace the journey from the first sequencing of our genetic code to the game-changing implications this has for personalised medicine today.

Listen to it **here**.

HoFH Patient Ambassadors Share Their Journey at SOLFED’s 10th Medical Day in Lyon

At SOLFED's 10th medical day in Lyon, France, on September 27, 2024, our FH Europe ambassadors, Maria Nassif and Chyrel Lichaa, shared their personal experiences of living with HoFH. Chyrel highlighted the challenges in Lebanon, including limited access to treatments, and her advocacy efforts to improve healthcare. As an example of how excellent care can change lives, Maria talked about her experiences with LDL apheresis in France and Lebanon. The importance of international cooperation and patient advocacy in enhancing

HoFH awareness and treatment is highlighted by their motivational stories

Read more about it **here**.

Celebrating the 25th Anniversary of the Portuguese FH Study

FH Europe proudly participated in the 25th anniversary celebration of the Portuguese Familial Hypercholesterolaemia (FH) Study (EPHF), founded by Prof. Mafalda Bourbon at the Instituto Nacional de Saúde Doutor Ricardo Jorge in 1999. The study has played a pivotal role in uncovering the genetic causes of FH and advancing research in genetics and precision medicine.

During the event, FH Europe's CEO, Magdalena Daccord, presented on The Prague Declaration and the Patient Ambassadors' Programme, emphasising global cardiovascular health and patient advocacy. The conference brought together health authorities, researchers, geneticists, and cardiologists, with international experts sharing best practices from Germany, the Netherlands, and Slovenia. Two FH patients also shared their stories, marking a significant moment in public patient engagement.

We congratulate Prof. Bourbon and the EPHF team on 25 years of remarkable achievements!

The CV Prevention & Intervention Conference in Warsaw

FH Europe Foundation proudly participated as a patron at the 2nd edition of the “Prevention & Intervention—where preventive cardiology meets interventional cardiology” conference in Warsaw, Poland. Magdalena Daccord, CEO of the FH Europe Foundation, and Agnieszka Wołczenko from Polish patient organisation EcoSerce, spoke on behalf of patients and citizens, and participated in a panel on patient centricity that highlighted the significance of cardiovascular health prevention and lifelong management.

This year’s theme, “Lifetime management of cardiovascular risk and disease—from the young to the elderly,” highlighted the need for early diagnosis and treatment. With the upcoming Polish EU Presidency, FH Europe Foundation underscored the importance of a cardiovascular health plan that prioritises patient voices and prevention across Europe.

The panel included Magdalena Daccord, Agnieszka Wołczenko, MP Elżbieta Gelert, Senator Agnieszka Gorgoń-Komor, Prof. Marek Gierlotka – incoming President of the Polish Cardiac Society, Prof. Marta Kaluzna, and Prof. Izabella Uchmanowicz, moderated by Marta Sułkowska.

Read more about it here.

NETWORK
NEWS

Austria - FHchol

FHchol Austria General Assembly and Expert Talks Once a year, FHchol Austria members gather for the general assembly at Vienna’s Hotel Regina. Chairwoman Anna Andrea Böhm presented the organisation’s activities and upcoming plans. A touching video featuring Lena, Gaby Hanauer-Mader's daughter and the inspiration behind the founding of FHchol Austria in 2011, was shown. In the video, Lena encourages everyone affected by FH to undergo genetic screening.

You can watch the video **here**.

In honour of the late founding president, Gaby Hanauer-Mader, a special achievement award was created. This year, it was awarded to Monika Cermak, a dedicated board member since the organisation’s inception. Congratulations, Monika!

The assembly was followed by expert talks. Michaela Stögerer-Lanzenberger discussed FH treatment in women, and Reinhold Innerhofer highlighted the importance of lifestyle for those with FH. The evening concluded with dinner and valuable discussions among the 27 participants.

Prepared by FHchol Austria

Ireland - Croí

Croí Heart & Stroke Charity Launches the Croí Connects Podcast

Introducing the Croí Connects Podcast, a new platform where heart, stroke, and cardiovascular health take centre stage. Croí—meaning "heart" in Irish—embodies the core of what this charity stands for: heart health, education, and prevention. In this series, listeners can explore important topics, gain insights from medical experts, and hear personal stories that shine a light on cardiovascular well-being.

In the first episode, Annie Costelloe, Croí’s Head of Patient and Community Engagement, interviews Dr. Patricia O’Connor, Director of the Lipid Clinic at St. James’s Hospital, about Familial Hypercholesterolemia (FH) and its rare form, HoFH. They discuss the underdiagnosed, potentially fatal genetic condition, highlighting the difference between common high cholesterol and genetic FH. As a proud member of FH Europe Foundation, Croí is raising awareness to help families recognise this serious condition.

If you or a loved one has unexplained high cholesterol or a history of early heart attacks, it might be FH. For support, contact the free Croí nurse helpline, available Monday to Friday, 9am – 5:30pm, at 091 544310 or healthteam@croi.ie. You can also register for weekly online health chats on: https://croi.ie/croi-connects/

Croí Connects – Podcast Links:

- **Apple Podcasts**
- **Spotify**
- **Podchaser**
- **iHeart**
- **Listen Notes**
- **Player FM**

Watch the preview of the podcast **here**.

Prepared by Croí

FRANCE – ANHET.F

French patients keep on fighting for the implementation of FH paediatric screening

An important update from France concerning FH Paediatric Screening! On October 22nd, Senator **Philippe Moullier**, Chairman of the Committee on Social Affairs, and **Anhet.f** brought together the leading scientific experts in the area of familial hypercholesterolaemia, as well as representatives of 14 societies, to ask parliamentarians to commit to FH paediatric screening and to launch a pilot study in France. The meeting was attended by Maria Nassif, FH Europe Foundation and Anhet.f HoFH Patient Ambassador.

The next step is the preparation of a bill on paediatric cholesterol screening.

Prepared by Anhet.F

Italy - ANIF

ANIF Supports Art Therapy Initiative to Raise Awareness for HoFH
In October, ANIF took part in a socially impactful event supporting people with disabilities, organised by the National Association of Knights of the Italian Republic. Focused on the theme of Art Therapy—the healing power of colours and art as a bridge of solidarity—the event invited various patient associations to display artwork created by their members. ANIF’s contribution helped raise awareness of Homozygous Familial Hypercholesterolemia (HoFH) and highlighted the important European network, FH Europe Foundation, reaching an audience that included regional officials and journalists.

Prepared by ANIF

Lithuania - Lithuanian Heart Association

Challenges in Contemporary Lipidology

On October 24, a conference titled "News and Challenges in Contemporary Lipidology" was held to highlight vascular health. Organised by the Lithuanian Heart Association in collaboration with the Heart and Vascular Diseases Clinic at Vilnius University, the event showcased national achievements in the prevention and diagnosis of cardiovascular diseases.

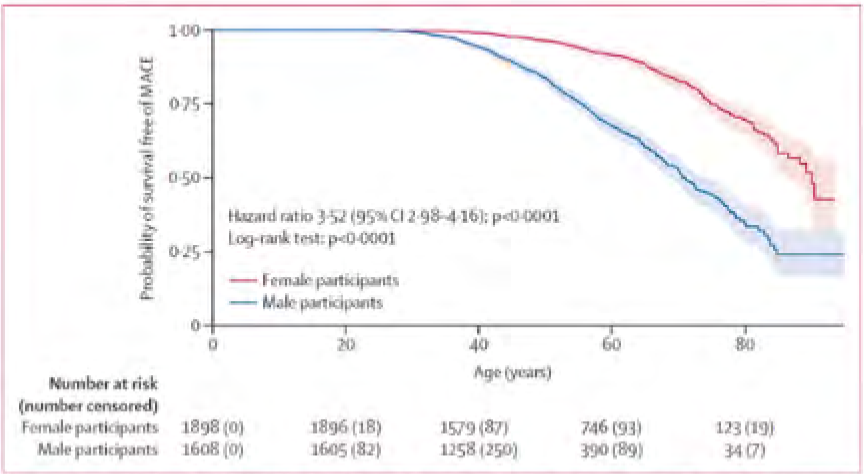
Key discussions covered heart disease risk models, personalised treatments for hyperlipidaemia, early diagnosis of familial hypercholesterolaemia, the importance of Lp(a), and the role of epigenetics in assessing heart disease risk. The aim was to encourage the medical, academic, and wider communities to engage with these vital topics.

Prepared by Lithuanian Heart Association

Spain – Fundación Hipercolesterolemia Familiar

The burden and risk of ASCVD are markedly lower in females than males with familial hypercholesterolaemia

The Spanish FH Foundation is pleased to share their article titled: Long-term sex differences in atherosclerotic cardiovascular disease in individuals with heterozygous FH in Spain: a study using data from SAFEHEART and published in September in Lancet Diabetes and Endocrinology.



Hazard ratio 3·52 (95% CI 2·98–4·16); p<0·0001
Log-rank test: p<0·0001

Number at risk (number censored)					
Female participants	1898 (0)	1896 (18)	1579 (87)	746 (93)	123 (19)
Male participants	1608 (0)	1605 (82)	1258 (250)	390 (89)	34 (7)

Kaplan–Meier curves for survival free of MACE from birth to end of follow-up in female and male participants with familial hypercholesterolaemia
MACE=major adverse cardiovascular events.

The study includes 3506 adults with genetic diagnosis (54% of the study were female). The mean age was 46 years, and median follow-up was 10.3 years. Major adverse cardiovascular event-free survival from birth was lower in males than females. The results show that there are important sex differences in cardiovascular risk over the long term, with a markedly lower burden of ASCVD in females than males, independent of age, standard cardiovascular risk factors and lipid-lowering medication. Additionally, ASCVD events occurred approximately 10 years later in female than male participants.

Read more about it **here**.

Evinacumab has been approved in Spain
Following collaboration between industry and patient organiation the Spanish FH Foundation, Evinacumab was approved and reimbursed starting in August for patients with homozygous FH from 5 years of age. The commitment and support of the Spanish FH Foundation has allowed the global and free access to FH treatment.

Prepared by Fundación Hipercolesterolemia Familiar

The Netherlands – VrouwenHart

New Book Co-authored by Caroline Verhage, Founder of VrouwenHart, Highlights Women's Heart Health

Caroline Verhage, founder of VrouwenHart in The Netherlands, co-wrote a book, Women Also Get a Heart Attack, released last month. This powerful book features poignant stories from women, paired with medical insights from cardiologist Jobst Winter, shedding light on a critical yet often overlooked topic.

Cardiovascular disease remains the leading cause of death among women, with an average of 54 women dying daily compared to 52 men. The book reveals how symptoms frequently differ from those experienced by men, resulting in misdiagnoses and delayed treatments. Key themes explored include symptoms and conditions explained by the cardiologist, real-life experiences of women with heart disease, the impact on lifestyle, and guidelines for improved care.

We at FH Europe Foundation extend our heartfelt congratulations to Caroline on this significant contribution to women's health.

Read more about it in Dutch here.

United Kingdom – Heart UK

Cholesterol & You: Understanding and Taking Action for a Healthier Heart
October is National Cholesterol Month in the UK, and Heart UK highlights that nearly half of UK adults have elevated cholesterol levels, a significant risk factor for heart disease. Their goal is to raise awareness about cholesterol, empowering individuals to make informed decisions and take proactive steps to lower their high cholesterol levels for better heart health.

Read more about it here.

Prepared by Heart UK

Global Heart Hub

Global Heart Unite Summit 2024

Global Heart Hub is thrilled to announce the 4th Annual Unite Summit, taking place in Dublin, Ireland, from November 3-5, 2024. This event will bring together the cardiovascular disease (CVD) patient community to explore the challenges of living with connected, long-term, and multiple conditions.

The Summit will focus on the interconnected nature of CVD and related conditions such as stroke, diabetes, kidney, liver, and mental health. By uniting these patient communities, we aim to improve care, advance research, enhance patient outcomes, and advocate for better health policies.

Early and coordinated treatment is essential for managing CVD and its connected conditions, as they can significantly impact both physical and mental health. The Summit will highlight the need for healthcare systems to adapt to provide more efficient and effective treatment, ensuring patients receive the best care possible for a better quality of life.

Prepared by Global Heart Hub

PARTNER
NEWS

European Alliance for Cardiovascular Health - EACH

Rising to the challenge: time for action on cardiovascular health

On November 18, 2024, the European Alliance for Cardiovascular Health (EACH) will convene a significant event in Brussels addressing the pressing issue of cardiovascular diseases (CVD) in Europe, where over 60 million individuals are affected. CVD remains the leading cause of death and disability across the continent, contributing to over €282 billion in healthcare costs annually.

The event will leverage the forthcoming Council Conclusions on cardiovascular health, spearheaded by the Hungarian Presidency, and reflect the commitment outlined in the European Commission President's political guidelines. With a focus on reducing mortality and enhancing quality of life for those at risk or living with CVD, the gathering aims to facilitate dialogue among EU and national stakeholders.

Moderated by Prof. Michal Vrablik from Charles University, the event will feature insights from Members of the European Parliament, European Commission representatives, and health ministry officials, pointing out the national best practices and strategies for improving cardiovascular health across Europe.

In a powerful addition to the event, we are pleased to welcome the Rijken Family. Marc, Manon, and their three teenage daughters bring a poignant perspective as they share their collective experience with elevated Lp(a), a familial lipid disorder that significantly increases the risk of CVD in every 5th person. As passionate advocates for the cardiovascular community and active Ambassadors with FH Europe Foundation, they will highlight the importance of early diagnosis and prevention strategies within CVD action plans. Through their narrative, the Rijken Family will emphasize the collective responsibility to uphold the right to cardiovascular health for all Europeans, regardless of age, sex, or postcode.

Learn more **here** or register **here**.

European Patients' Forum

Advancing Patient-Centred Health Policies: Highlights from EPF's Recent Event

On October 16, 2024, the European Patients' Forum (EPF) hosted the High-Level Policy Event "Towards a patient-centred EU mandate: Health policy with and for patients" in Brussels. The event highlighted the crucial role of patient representation in healthcare policymaking. EPF President Marco Greco kicked off the discussions, promoting the #Vote4Patients campaign and advocating for clear definitions of patient organisations. Keynote speakers included European

Commissioner Stella Kyriakides, who stressed the necessity of amplifying patient voices, and Dr Hans Kluge from WHO Europe, who highlighted the value of patient experiences.

Panels explored the continuum of patient engagement, addressing challenges and opportunities across various sectors. The event concluded with insights from MEPs on crucial issues like access to medicines and health literacy, underscoring EPF's commitment to fostering a more inclusive healthcare environment for all patients.

Read more about it here.

EURORDIS

Launch of the Patient Partnership Hub: Strengthening Patient-Clinician Collaboration

In October 2024, EURORDIS-Rare Diseases Europe proudly launched the Patient Partnership Hub, an innovative online platform designed to enhance collaboration between patients and clinicians in healthcare. This Hub curates essential resources and tools aimed at fostering patient partnership, particularly within the framework of European Reference Networks (ERNs).

The Patient Partnership Framework highlights a mutual relationship where the input of individuals living with rare diseases informs decision-making and collaborative activities. The Hub aims to empower both patient representatives and healthcare professionals by providing accessible guidance on best practices for effective collaboration.

Currently featuring resources developed by EURORDIS, the Hub will expand to include contributions from other organisations. Users can navigate its content easily, using a powerful search function to find relevant information. A demonstration webinar will take place on November 15, offering participants insights into the Hub’s features.

This initiative marks a significant step forward in ensuring healthcare services effectively meet the needs of those living with rare or complex conditions.

Read more about it here.

ERDERA

Creation of a new Rare Disease Research Alliance

The European Rare Disease Research Alliance (ERDERA) takes over EJPRD to deliver concrete health benefits to rare disease patients in the next decade by advancing prevention, diagnosis and treatment research. Read more about this new initiative in the official press release **here**.

World Heart Federation - WHF

World Heart Day Impact: Join the Fight for Heart Health Advocacy

Even though World Heart Day has passed, the World Heart Federation remains committed to its mission of improving cardiovascular health worldwide. A major goal is collecting 1 million signatures by the 2025 UN High-Level Meeting, where a new political declaration on noncommunicable diseases, including heart disease, will be up for adoption. This initiative highlights the urgent need for stronger CVD prevention and treatment.

The Heart Care Foundation in Bangladesh is currently leading in gathering signatures, demonstrating remarkable dedication to heart health. WHF encourages all members to stay involved by downloading and promoting the petition widget. The organisation with the most signatures will receive a grant to support their 2025 World Heart Day campaign.

Read more about it **here**.

Vistatec

Vistatec Launches Life Sciences Newsletter

We are pleased to share that Vistatec, our longstanding partner in many awareness campaigns focusing on content translations and localisation, has now launched its *Life Sciences Newsletter*. Feel free to sign up for interesting content concerning life sciences, translations, localisation, and from time to time also updates relevant to familial hyperlipidaemias.

Read more about it **here**.

NEW
PUBLICATIONS

Debunking the Myth – FH Does Not Protect Against Diabetes

The FHSC team, led by Imperial College London, has published a study in The Lancet Diabetes & Endocrinology debunking the misconception that familial hypercholesterolaemia (FH) protects against type 2 diabetes.

Analysing data from 24,000 FH patients worldwide, the study found a diabetes prevalence of 5.7%, similar to the general population. This challenges the belief that FH offers protection, highlighting the importance of lifestyle management.

The research also shows that while statin use increases diabetes risk, obesity remains the most significant factor. Managing weight is crucial to improving health outcomes in FH patients.

Read more about it **here**.

SAVE THE DATE

- **1 November** - FCS Awareness Day
- **8 - 10 November** - FHEF Annual Network Meeting 2024
- **16-18 November** - American Heart Association Conference
- **4-6 December** - International Symposium on Atherosclerosis

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