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

FH Europe Foundation Summer 2024 Heart Beat Newsletter

Welcome to the special Summer edition of the Heart Beat Newsletter! While we anticipate an eventful September with both FH Awareness Day on September 24 and World Heart Day on September 29, here are also some highlights from the impact-full months of summer.

Firstly, a warm welcome to two new members of our Network from the Netherlands and Singapore. Yes, Singapore! You will find important updates about our advocacy for access to HoFH treatment work followed by a Healthy Heart Law announcement in Germany. We are pleased to share about Hungary's EU Presidency high-level conference dedicated to the European Cardiovascular Health Plan and the World Heart Federation petition.

There is important news for the rare lipids' community. New data shows positive outcomes from a clinical trial in FCS. The HoFH Awareness Day webinar trilogy kicks off in 2 weeks. And much more!

We're also bringing you news from Austria, Czechia, the UK, and Hungary, along with exiting news from our member to-be, Croatia.

Finally, it is time to ensure you got your Annual Network Meeting invitation to join us in Vienna!

Enjoy reading and have a lovely week ahead!

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FH EUROPE FOUNDATION NEWS

Our Network is Growing: Welcoming Two New Members

We are excited to share that our network continues to grow with the addition of two new members: **Stichting VrouwenHart** from the Netherlands and FHCARE Singapore. These organisations bring valuable expertise and a shared commitment to advancing our mission, further enriching our global community.

Stitching VrouwenHart joins us with a strong commitment to championing women's heart health. As a leading non-profit in the Netherlands, VrouwenHart has been pivotal in raising awareness about cardiovascular disease in women, an often-overlooked demographic in research and treatment. Their dedication aligns perfectly with our mission, and we look forward to continued collaboration, building on past successes like our recent FH Awareness Day webinar.

Read more about it **here**.

The collaboration with **FHCARE Singapore** marks a significant step in expanding our impact in the Asia-Pacific region. Established in 2016, FHCARE Singapore has been at the forefront of supporting individuals with familial hypercholesterolaemia (FH). With a focus on improving the diagnosis and management of FH, they have made significant strides in patient support and awareness. Their inclusion strengthens our reach in the Asia-Pacific region, opening up new opportunities for collaboration and progress.

Read more about it **here**.

We look forward to the meaningful contributions both organisations will bring to our network as we work together to improve the lives of those affected by familial hyperlipidaemias worldwide.

FHEF issues a statement advocating for access to lifesaving treatments for HoFH in Germany

In our dedication to supporting individuals and families affected by familial lipid disorders, we have issued an urgent statement to the Federal Joint Committee (G-BA) in response to the decision on an ANGPTL3 inhibitor (Evinacumab) for patients with homozygous familial hypercholesterolaemia (HoFH) aged 12 years and older in Germany.

The FHEF statement has been prepared in collaboration with international HoFH patient ambassadors and health care and policy experts and endorsed by the leading scientific society—the European Atherosclerosis Society (EAS). It emphasises the importance of considering the underlying genetic causes of the disorder and the latest available scientific evidence while recognising the burden of the disease and the patient's lived experiences in health decisions in Germany. The statement underscores the need for personalised care and the recognition of patient safety and health economic arguments in the treatment of HoFH.

As the G-BA plays a pivotal role in determining which treatments are reimbursed by statutory health insurance in Germany, we have strongly urged them to reconsider their decision and prioritise the health and well-being of HoFH patients in Germany.

We remain committed to engaging in dialogue to ensure that HoFH patients receive the care they need. However, this statement has far-reaching consequences in the future, also for other inherited lipid disorders and access to novel therapies in a country, where apheresis is a preferred standard of care by the healthcare systems and where patients' voice is not heard.

Read the statement **here**.

Advocating for a Comprehensive EU Cardiovascular Health Plan

In the first week of the Hungarian EU Presidency, the FHEF delegation participated in a high-level conference on cardiovascular health in Europe, our third EU Presidency meeting. The event in Budapest highlighted the rationale for establishing a European Cardiovascular Health Plan. During the panel discussion, we were able to emphasise the importance of raising awareness about inherited lipid conditions, such as familial hypercholesterolaemia (FH) and elevated Lp(a), as key genetic risk factors for cardiovascular disease (CVD).

The meeting offered an opportunity to showcase successful examples of FH early screening and detection programs, underscoring the need for urgent action to prevent heart attacks early in life. FH, including HeFH and HoFH, along with elevated Lp(a) and FCS, can lead to early and severe heart issues, but early detection and treatment can significantly and effectively reduce CVD.

With CVD causing 1.7 million deaths annually in Europe and costing 282 billion EUR, it's clear that a comprehensive Cardiovascular Health Action Plan is essential. Europeans deserve better cardiovascular health.

Discover more about the conference, including highlights and key takeaways, and learn how FH Europe is working with international leaders to drive innovation and personalised prevention in tackling CVD **here**.

Three weeks to go to FH Awareness Day 2024 – Join Us!

FH Awareness Day is a global call to action to educate ourselves and others about familial hypercholesterolaemia (FH), a common. Still, an often-misunderstood genetic condition is estimated to affect 1 in 300 people and is estimated to have, but only 10% have been identified. Our 2024 campaign will therefore focus on three key objectives that will help us Prevent the Preventable!

- **Raising awareness** to clarify the difference between high cholesterol and FH for the general public.
- **Advocating for early screening** by highlighting the importance of early detection and personalised prevention through genetic screening.
- **Promoting CVD prevention** will strengthen advocacy efforts for cardiovascular disease (CVD) prevention both in Europe and globally.

This year’s campaign will build on ongoing projects, such as PERFECTO and PerMed FH, and align with broader political movements like the EU Cardiovascular Health (CVH) Plan and the World Heart Federation's (WHF) CVH Petition.

On this occasion, we have prepared for you a toolkit with a set of social media visuals, messages, a press release, a social media photo frame, and an email signature. On the actual day, we will host a special webinar, so make sure you amplify the voice of the global community.

Read more about it here.

Don’t miss the webinars Trilogy - HoFH Treatment Options Today and What Lies Ahead

World-leading researchers and medical experts, together with HoFH Patient Ambassadors, will present in a series of very dynamic, focused, and informative webinars ***Exploring the Horizons of HoFH Treatment: Current Options and***

Future Perspectives.

These webinars will talk about how HoFH is treated right now and look at new treatments that might change how patients are cared for in the future. They will be co-moderated by Chyrel Lichaa and Prof. Albert Wiegman.

Register for the webinars now!

- ***September 17: Towards precision medicine and personalised prevention in HoFH***: genetics and the novel therapies – gene therapies with Prof Mafalda Bourbon and Prof Steve Humphries, Michelle Watts and Thanos Pallidis.

- ***September 19: The golden standards in HoFH***: statins, ezetimibe and apheresis with Dr Julia Brandt, Dr Antonio Gallo and Elsie Evans.

- ***September 26: The recent trio of treatments in HoFH***: PCSK9 inhibitor, lomitapide and evinacumab with Prof Luis Masana: Lomitapide and Dr Antonio Gallo, Prof Raul Santons, as well as Maria Nassif and Marwa Sadik.

Don’t Miss Your Chance to Participate in the HoFH Logo Competition!

The deadline for submitting your design for the HoFH Logo Competition is approaching fast.

Whether you're a seasoned designer or simply passionate about raising awareness or drawing and telling a good story with your art, this is your unique chance to be part of something very special.

The purpose of the **HoFH Awareness Day logo** is to have a global visual, an image that will represent and unite the HoFH community now and for years to come.

For more information, visit the **Logo Competition web page**, meet the judges, and mark the due date to submit your visual: **September 24, 2024** (FH Awareness Day).

Annual Network Meeting 2024 – Make sure you join!

The website for this year's FHEF Annual Network Meeting is live, and webinar registrations are now open! Join us as we kick off with four webinars starting on October 3, 2024, leading up to the in-person meeting in Vienna on November 8–10.

So, check out your inbox for a personal invitation to join us in person or simply turn up at the open to public webinars. But first register to secure your place!

We look forward to seeing you there as we drive change together!

Note: The webinars will be open to the public, while in-person participation will be by invitation only. Visit the official webpage and register **here**.

Rare Disease: Patient Passport

Together with CAMRARE we are pleased to share the “This is Me” Rare Patient passport with our community. This passport is designed to address the unique needs of individuals with rare conditions by providing comprehensive yet personalised information about each patient, including the challenges you face and the support you need. It serves as a valuable tool to help you communicate with others, allowing them to quickly understand how they can support you in various environments. You can register for it **here**.

Make sure to select the **FH Europe Foundation** from the list when registering for a 'This Is Me' Rare Patient Passport.

If you have trouble accessing the PDF, you can download it **here**. For added convenience, you can create a QR code from your PDF using **this free tool**.

Simply click "Create QR Code," select your PDF, upload it, sign in (it's free), and download the image of your QR code to keep your Patient Passport handy on your phone.

NETWORK NEWS

Austria - FHchol

FH Symposium in Vienna FHchol invites you to join the FH Symposium on September 11, 2024, in Vienna, titled "Unsichtbares Erbe: Genetische Cholesterin-Stoffwechselstörungen rechtzeitig erkennen, verstehen und erfolgreich behandeln" ("Invisible Inheritance: Identifying, Understanding, and Successfully Treating Genetic Cholesterol Metabolism Disorders"), at the Van Swieten Saal, Medical University of Vienna. The symposium, running from 13:30 to 18:40, will feature presentations from international and national experts on diagnosing and treating familial hypercholesterolaemia (FH), which affects 30,000 people in Austria. Among speakers Nicola Bedlington, FHEF’s Sr Policy Advisor. Participants will be able to engage in a "Meet the Experts" session and benefit from free lipid testing. Space is limited to 200 participants, so early registration is encouraged.

Read more about it here.

Prepared by FHchol

Croatia - Croatian Dyslipidaemia Patient Organisation

Run4FH in Croatia: Join the Movement! On Sunday, September 22, Croatia will host the Run4FH event, a fantastic initiative promoting physical activity and raising awareness about high cholesterol, including genetic conditions like HeFH and HoFH.

Organised in collaboration with the Croatian Association of Patients with Dyslipidaemia, RunCroatia, and the Croatian Hypertension League, this event invites participants to "run 5 km for cholesterol under 5 mmol/l."

The run coincides with FH Awareness Day and encourages everyone to get active while spreading the important message about cholesterol management.

Register for the run here.

Prepared by Croatian Dyslipidaemia Patient Organisation

Czech Republic - ČAKO

9th Annual FH Week in the Czech Republic This September, cities across the Czech Republic will host the 9th annual FH Week, dedicated to raising awareness about Familial Hypercholesterolemia FH and the importance of knowing your cholesterol levels. Events at eight locations will offer free cholesterol screenings, ensuring participants are informed about their heart health.

This year, FH Week expands its focus to include targeted education on Lp(a), with measurements available in selected cities. Attendees can also look forward to insightful lectures and a press conference discussing the latest in cholesterol management.

ČAKO will proudly join the FHEF social media campaign, helping spread vital information nationwide.

Prepared by ČAKO

Hungary - SZÍVSN

SZÍVSN Hungary has been actively engaging in important discussions and educational events aimed at improving heart health

Stress makes us sick, yet we don’t deal with it
Barbara Mihálycsik, a recent guest in SZÍVSN’s lecture series, shared valuable insights on stress management. Drawing from her experience in pulmonology and cardiology wards, she highlighted how stress is often overlooked by patients despite its significant impact on health. Discover more about her findings **here**.

Only together can we be strong – Let’s fight for women’s health!
SZÍVSN recently participated in a roundtable discussion focused on women’s health, emphasising the importance of collective action in addressing these issues. Read the full recap **here**.

Telemedicine for managing heart failure
Dr. Gergely György Nagy, PhD, delivered an engaging webinar on the use of telemedicine in Miskolc to support heart failure patients. The session was

attended by both nurses and patients, highlighting the growing role of telemedicine in patient care.

Strategies to Lose Weight in a Heart-Friendly Way
Join Julia Perger, a clinical nutritionist with an MSc, for an upcoming webinar on heart-friendly weight-loss strategies. The lecture will provide science-backed tips on creating sustainable habits that promote both weight loss and heart health.

For more information, visit SZÍVSN’s website here.

Prepared by SZÍVSN

We invite you to our new EMPOWER webinar session!

A Patient’s Guide to Shared Decision-Making for Heart Valve Disease

Thursday, 19 Sept

11:00 EST | 15:00 UTC
16:00 IST | 17:00 CET

Book your free place now!

Global Heart Hub

Heart Valve Voice Canada

UK - Global Heart Hub

Webinar: A Patient’s Guide to Shared Decision-Making for Heart Valve Disease The Global Heart Hub, in collaboration with Heart Valve Voice Canada, invites you to join a special webinar on September 19, 2024, focused on shared decision-making for heart valve disease. This patient-centred event will take place online at 5:00 PM Central European Time.

A panel of experts will guide you through the principles of shared decision-making, empowering you to actively participate in your care decisions and improve your health outcomes. Don’t miss this valuable opportunity to take control of your healthcare journey.

Register now and secure your spot here.

Prepared by Global Heart Hub

NEWS
FROM AROUND THE WORLD

FH Australia

Australia now has a dedicated patient organisation for those living with Familial Hypercholesterolaemia (FH). FH Australia is highly active on social media, working hard to raise awareness and provide support for individuals affected by FH. If you're in Australia and seeking a supportive community, keep an eye out for FH Australia.

Read more about it **here**.

Germany – the Healthy Heart Law

At the end of August, the German government announced "Healthy Heart Law"! Germany's new "Healthy Heart Law" (Gesundes-Herz-Gesetz) marks a major step forward in combating cardiovascular diseases. The draft of the law was accepted by the ministers, but not by the Parliament yet.
Key highlights:

- Expanded Screenings: Early detection of lipid metabolism disorders in children, targeting familial hypercholesterolaemia
- Heart Health Check-ups: New check-ups at ages 25, 40, and 50
- Pharmacy Involvement: Pharmacies to offer more heart disease prevention services
- Better Access: Easier access to lipid-lowering drugs and smoking cessation aids.

The aim is to detect heart disease risks earlier and improve preventive care across all age groups.

More in German **here**.

World Patients Alliance

World Patient Safety Day Webinar on Diagnosis

Diagnosis is a critical aspect of patient safety, with errors contributing to 16% of preventable harm in health systems. In response, World Patient Safety Day 2024 is centred on the theme, "Improving Diagnosis for Patient Safety." The

World Patients Alliance is organising an important webinar on September 18 at 9 a.m. ET.

This event will gather experts, patients, and advocates to discuss practical strategies for reducing diagnostic errors and fostering better collaboration in healthcare. It’s an essential conversation for anyone committed to improving patient safety. Don’t miss out—register today!

Read more about it **here**.

PARTNER NEWS

EAS - FHCS

Highlights from the FHSC Steering Committee Meeting at the EAS 2024

On May 26, 2024, over 80 national lead investigators from the Familial Hypercholesterolaemia Study Collaboration (FHSC) and key collaborators gathered in Lyon, France, for a closed-door session preceding the 92nd European Atherosclerosis Society (EAS) Congress. The meeting featured insightful presentations, including updates and ongoing analyses from the FHSC Coordinating Centre, national leads, and close collaborators. Prof. Kausik K Ray, the Global PI of the FHSC, expressed gratitude to all the national lead investigators for their contributions to the growth of the datasets maintained in the FHSC coordinating centre, located at Imperial College London. Speakers from the FHSC Coordinating Centre included Mr Christophe AT Stevens, Senior Data Manager and Software Developer; Dr. Irene Karungi, Research Assistant; and Dr. Amany Elshorbagy, Lead Cardiovascular Disease Epidemiologist. The speakers

Provided updates to the attendees on the FHSC infrastructure and ongoing analyses. Additionally, Belgium’s National Lead Investigators shared insights on how they have submitted follow-up data to the coordinating. The session concluded with a presentation from FH Europe’s Executive Director, who provided an update on FH Europe’s latest initiatives.

EURORDIS

Reminder: Participate in the Rare Barometer Survey on the Impact of Rare Diseases

EURORDIS encourages you to participate in the new Rare Barometer survey, which focusses on how rare diseases affect daily life. If you haven't responded yet, please complete this short survey by September 8, 2024—it should take no more than 20 minutes.

Open to individuals living with a rare disease and their families worldwide, the survey is available in 25 languages. Your input will help strengthen advocacy efforts for better access to rights and societal participation for the rare disease community.

To participate in the survey, click **here**.

Nominations Open for the EURORDIS Black Pearl Awards 2025

EURORDIS invites nominations for the Black Pearl Awards, taking place in February 2025. These prestigious awards honour the exceptional contributions of rare disease advocates, patient organisations, policymakers, scientists, and companies.

With ten awards available, the Black Pearl Awards recognise excellence in areas like volunteering, scientific innovation, and impactful awareness-raising projects. If you know someone who makes a significant impact in the rare disease community, nominate them to be honoured at this special event.

Read more about it **here**.

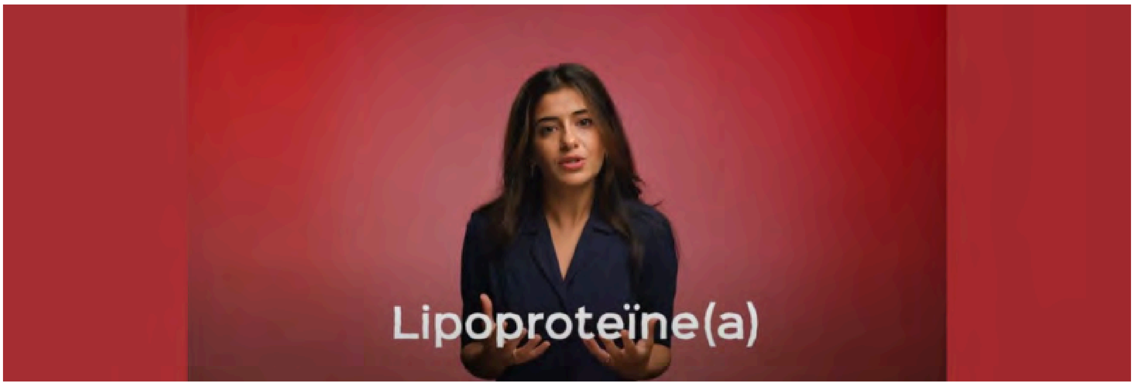
European Alliance for Cardiovascular Health - EACH

Advocating for a Comprehensive EU Cardiovascular Health Plan

As a dedicated partner alongside 18 other organisations in the **European Alliance for Cardiovascular Health (EACH)**, we are advocating for the establishment of an EU Cardiovascular Health Plan.

Cardiovascular Disease (CVD) is the leading cause of death both in Europe and globally, underscoring the urgent need for decisive action. The EU institutions are committed to evidence-based decision-making, and with CVD being the top cause of mortality in the Union, costing over €100 billion—more than the entire EU budget—the evidence is clear: robust policy action is essential.

Read more about the plan **here**.



LEEFH

New Lp(a) explainer with Dr Shirin Ibrahim (with English subtitles)

Dr Shirin Ibrahim from Amsterdam UMC presents a concise 6-minute video explaining the essentials of Lp(a), a lipid particle composed of an LDL particle and an apolipoprotein(a) tail. In this brief but informative video, Dr. Ibrahim clearly outlines the significant health risks associated with elevated Lp(a) levels, including an increased risk of cardiovascular disease.

This updated version, now available with English subtitles, ensures that even more viewers can access and understand this important information on heart health.

Watch the video **here**.

World Heart Federation - WHF

Sing a global petition this World Heart Day 2024

On September 29, the FH Europe Foundation will be observing World Heart Day. Please join us in **signing a global petition** initiated by the World Heart Federation **calling on all governments to establish a Cardiovascular Action plan to save lives in their countries.**

Cardiovascular disease (CVD) is the world's number one killer. It kills more people than all forms of cancer and chronic lower respiratory disease combined. Conditions affecting the heart or blood vessels – such as heart attack, stroke and heart failure – claim more than 20.5 million lives each year.

Current efforts to combat CVD at a national level are failing almost everywhere in the world. Yet, 80% of premature CVD related deaths are preventable. And leaders have known this for decades.

A Cardiovascular Health Plan acts as a strategic tool, reducing premature deaths from heart disease and stroke, while also cutting healthcare costs and productivity losses, saving hundreds of billions of dollars annually worldwide.

As a proud member of the World Heart Federation, FH Europe Foundation believes it is our responsibility to support the urgent need for a global **Cardiovascular Health Plan**. In Europe specifically, we have been advocating for the CVH plan under the umbrella of the European Alliance for Cardiovascular Health (EACH) for close to 2 years.

Our dear community, we urge you to **sign the petition** and use the social media application to spread the message far and wide to **help us unite and save more lives.**

WHF Members' Workshop: USE ❤️ FOR ACTION—What's the Beat of Your Nation?

The World Heart Federation (WHF) invites its members to the upcoming "USE ❤️ FOR ACTION: What's the Beat of Your Nation?" workshop on Tuesday, September 10 at 14:00 CEST. This important session will bring together WHF members to share and discuss effective strategies for advancing cardiovascular health initiatives in their countries. As we approach World Heart Day, the workshop will also focus on how the theme can be harnessed to strengthen campaign efforts.

Register **here**.

FRESH
OF THE PRESS

A new hope on the horizon for patients with Familial Chylomicronaemia Syndrome (FCS).

On Monday, September 2, Arrowhead Pharmaceuticals presented pivotal Phase 3 data at the European Society of Cardiology Congress in London from the PALISADE study, which investigated plozasiran in patients with Familial Chylomicronemia Syndrome (FCS).

The study highlights the effects of plozasiran, a novel drug targeting FCS—a rare familial lipid disorder that causes extremely high triglyceride levels and significantly increases the risk of acute pancreatitis.

Key Findings from the Study:

- **Triglyceride Reduction**: Plozasiran achieved a substantial reduction in triglyceride levels, lowering them by up to 80%, compared to only 17% in those receiving a placebo.
- **Pancreatitis Prevention**: Patients treated with plozasiran showed a reduced risk of pancreatitis, with significantly fewer cases observed compared to the placebo group.

In terms of safety, the drug was generally well-tolerated, with a safety profile similar to placebo, although some patients with diabetes experienced mild increases in blood sugar levels.

What does it mean for patients with FCS? Plozasiran offers a promising new treatment to manage dangerously high triglyceride levels and reduce the risk of pancreatitis, which is a serious and common complication for those with FCS. It provides hope for better disease management and improved quality of life.

You can access the full press release, including a link to the official publication and slides from the congress, here.

SAVE THE DATE

- **17 September** - World Patient Safety Day and World Apheresis Day
- **17 September** - Webinar: Towards precision medicine and personalised prevention in HoFH: genetics and the novel therapies
- **17 September -** Webinar: The golden standards in HoFH: statins, ezetimibe and apheresis
- **24 September** - FH Awareness Day
- **26 September** - The recent trio of treatments in HoFH: PCSK9 inhibitor, lomitapide and evinacumab
- **29 September** - World Heart Day
- **1 November** - FCS Awareness Day
- **8 - 10 November** - FHEF Annual Network Meeting 2024

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