



FH Europe Heart Beat News February 2022

Welcome to our February newsletter. February is Heart Month for many European countries. This brings a chance for all of us to focus on our cardiovascular health. It has been a busy month for raising awareness of FH (Familial Hypercholesterolaemia), within FH Europe and beyond and there are plenty of updates to share.

Read on to hear about a webinar we are hosting on Rare Diseases Day (28th Feb) dedicated to Homozygous Familial Hypercholesterolaemia (HoFH). You'll find out how we all can contribute to a new report from The World Heart Federation called World Heart Vision 2030. In other FH Europe news, there's news of the appointment of two new Trustees to our board and a Senior Policy Projects Manager within our team.

Find out the latest developments from our European network below. In France, there was a response to the open letter we collaborated on, outlining the burden of FH in the context of CVD to the French President. Learn about a cholesterol education programme in Belgium, the results of an FH screening programme in Bavaria, Germany and awareness-raising activities in Latvia to promote women's heart health.

Last but not least, you'll find details of an important retrospective of a landmark global study into homozygous familial hypercholesterolaemia published in The Lancet.

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Forward



FH EUROPE
NEWS

Patient Trustees Appointment

FH Europe is excited to announce the appointment of [two new Patient Trustees](#) on our Board. We wish a warm welcome to Gergely Jambrik from Hungary and Annelies Doll from the Netherlands, who were officially appointed on Feb 16th 2022. To learn more about Gergerly and Annelies and the other members of our Board of Trustees visit [here](#).

Senior Policy Appointment

Our team on the ground is growing too! We are thrilled to be joined by Frazer Goodwin as our S Policy Projects Manager, who will be in charge of two strategic projects at FH Europe - development of national taskforces for the implementation of FH paediatric screening and our Ambassadors Program. Find out more about Frazer [here](#).

Rare Disease Day Webinar on HoFH

FH Europe is hosting a webinar on Rare Diseases Day - Monday, Feb 28th dedicated to Homozygous Familial Hypercholesterolemia (HoFH).

This multi-perspective discussion brings together international speakers to discuss recent scientific learnings that could positively influence countries' health policies.

We'll also explore the role of patient organisations in improving the lives of people living with severe and rare forms of inherited high cholesterol.

The event takes place from 6pm-7pm CET with simultaneous translation into German, Italian and French via Zoom. Livestreamed on Facebook in English.

Panel moderator

Magdalena Daccord, Chief Executive of FH Europe

Speakers

Thanos Pallidis (LDL Greece) and Michelle Watts (Avery's Fight, USA)

Prof. Kausik Ray (President of European Atherosclerosis Society, Lead of the Global FH Registry EAS FHSC, UK)

Nicola Bedlington, (Senior Policy Advisor to FH Europe, past General Secretary of the European Patients' Forum, Austria)

This event comes at a very exciting time, following a landmark publication in the Lancet on HoFH.

[Read more](#) and [register now](#).

A further webinar hosted by the Global Heart Hub will look at what cardiovascular disease advocates can learn from the rare disease community: read more in the updates from the partners.

France - Anhet.f

Last month, Anhet.f and FH Europe issued an Open Letter to the French President Emanuel Macron and representatives of the French Health Ministry. The letter outlined the burden of FH in the context of CVD and proposed solutions around FH paediatric screening to prevent the consequences of undetected and untreated inherited high cholesterol (FH) and HoFH.

Lionel Ribes, President of the French FH Patients Organisation, is pleased to share a response to the letter. The matter has been directed to the French Health Minister - an important step forward to addressing the urgency of #FHchildscreening in the country.

Latvia - Parsirdi.lv

Parsirdi.lv, in collaboration with Latvian leading cardiologists, started February with activities dedicated to Women's Heart Health Day - Go Red For Women.

The activities draw attention to the risk factors for women's heart health, encourage women to check their health, improve lifestyle choices or to start treatment if necessary.

According to the latest cross-sectional study of cardiovascular risks in the Latvian population, 61% of Latvian ladies have elevated LDL cholesterol. The risks of high cholesterol, including the need to pay attention to inherited and inherited disorders such as familial hypercholesterolemia, were a key focus.

Parsirdi.lv has compiled significant data and information about heart health and the risk factors for women via www.parsirdi.lv

Follow #FHOpenLetter on social media to stay up to date and to see the original response.

Germany - VRONI

In Bavaria, Germany, there's an update on the success of a programme for the detection of heterozygous FH known as VRONI. The study focused on children aged 5 to 14 years. Recruitment started in early 2021 and within the first months more than 380 pediatricians screened over 7500 children during their regular pediatric visits. Approximately 10% of these children exceeded the predefined LDL-C threshold of 130 mg/dl (3.34 mmol/l) and 67 children with pathogenic FH-Mutations were identified.

FH-positive children are registered and treated by specialised pediatricians and cardiologists. Certified training centres offer affected families FH-focused training courses.

For more information please visit <https://www.myvrni.de/>

Belgium - Cholesterol education program

In February, the Belgian Cardiological League announced the launch of a campaign to better understand #cholesterol, entitled "True/False: 11 preconceived ideas about cholesterol".

A series of statements on cholesterol are analysed and completed in a free information brochure in hospitals and on the website of the organisation.

Thanks to this awareness campaign, the Belgian Cardiological League aims to disentangle the true from the false of the received ideas that we have about cholesterol. Whether it's good or bad cholesterol, related cardiovascular risks, lack of knowledge of statins and familial hypercholesterolemia, this fatty substance will no longer hold any secrets for you.

For more visit their [website](#) in French and Dutch.

World Heart Federation

The World Heart Federation is currently working on an initiative called World Heart Vision 2030, a report that will address strategic challenges and opportunities that the cardiovascular health community will face over the next decade.

World Heart Vision 2030 will review key challenges and propose ways in which they can be turned into opportunities to improve cardiovascular health, reduce cardiovascular health inequalities and reduce the global burden of cardiovascular disease.

As a member of the WHF, FH Europe will participate in [a survey](#) to guide the work on the key domains and priority areas and share our thoughts and ideas in the report.

We encourage you to contribute by Sunday, 6th March, 2022. The feedback provided will inform the content of the report to be discussed during the World Heart Summit in late May 2022.

Global Heart Hub COVID-19 Response Campaign

As the pandemic continues across the globe, the Global Heart Hub is reemphasising the necessity to put your heart health before fear of COVID-19. They encourage you to never delay seeking medical help if experiencing a heart or stroke emergency. When your heart says so, #JustGo.

This important message is being spread through a poster campaign in partnership with pharmacies around the world and an international social media campaign.

To learn more and help promote this campaign, please click [here](#).

Join Global Heart Hub's Inspire Patient Advocacy session

Global Heart Hub would like to invite you to its next Inspire webinar on 7th March at 14:00 GMT (15:00 CET).

Join the conversation with Dr Durhane Wong-Rieger (President & CEO of the Canadian Organisation for Rare Disorders and Chair of the Canadian Heart Patient Alliance) and learn what cardiovascular disease advocates can learn from the rare disease community.

Register now free [here](#).

SAFE - Stroke Alliance for Europe (SAFE)

The Stroke Alliance for Europe has launched the European Life After Stroke series of free events for 2022. The first event on Friday 11th March 2022 (10.00-16.30 CET) includes two plenary sessions covering the value of self-management and communications after stroke. The first session will share new ways of thinking about and building the evidence base on self-management. The second plenary will focus on overcoming communication barriers which can be a challenge for people with stroke. They will feature a mix of presentations from eminent speakers and contributions from stroke survivors.

Find out more [here](#) or register [here](#).

Worldwide experience of homozygous familial hypercholesterolaemia: retrospective in The Lancet

HoFH is a rare inherited disorder resulting in extremely elevated low-density lipoprotein cholesterol levels and premature atherosclerotic cardiovascular disease (ASCVD). Current guidance about its management and prognosis stems from small studies, mostly from high-income countries.

This retrospective of a cohort study published in The Lancet assesses the clinical and genetic characteristics, as well as the impact, of current practice on health outcomes of HoFH patients globally.

The findings indicate that worldwide, patients with HoFH are diagnosed too late, undertreated, and at high premature ASCVD risk.

Greater use of multi-Lipid Lowering Therapy (LLT) regimens is associated with lower LDL cholesterol levels and better outcomes. Significant global disparities exist in treatment regimens, control of LDL cholesterol levels, and cardiovascular event-free survival, which demands a critical re-evaluation of global health policy to reduce inequalities and improve outcomes for all patients with HoFH.

Learn more [here](#).

**SAVE THE
DATE**

- **28th February** - FH Europe Rare Disease Day webinar
- **7th March** - Global Heart Hub webinar
- **11th March** - Stroke Alliance for Europe (SAFE) event
- **24th March** - Lp(a) Awareness Day - FH Europe Lp(a) Awareness Day webinar
- **21st -22nd April** - European Patients' Forum Congress
- **27 June - 1st July** - European Conference on Rare Diseases and Orphan Products