

FH Europe Heart Beat News May 2022

Welcome to May's newsletter! The month was packed with important events and new developments, which shift the paradigm from cardiovascular disease burden towards cardiovascular health promotion! To start there was the official launch of the Cardiovascular Health Plan for Europe by the European Alliance for Cardiovascular Health (EACH), coinciding with the publication of new report from the European Federation of Pharmaceutical Industries proposing specific recommendation towards better health system. Towards end of the month, there was the 7th edition of the World Heart Summit and the 90th EAS Annual Congress, where FH Europe with its Network was proudly representing the patients perspective.

Join us on June 15th at a EAS congress highlights webinar! As the European Commission allocates funding for Member States for prevention and health promotion, we will explain to you in a dedicated call on June 7th how you can benefit from it too.

Another highlight was the launch of our international survey on women with FH/HoFH alongside several European institutions on the International Day of Action for Women's Health.

And finally in this edition of Heart Beat we present to you the Lithuanian Heart Association (LHA), a new member to our growing network, with its FH national screening program.

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FH Europe welcomes a new member to the network

The Lithuanian Heart Association (LHA) has now joined FH Europe's growing network. LHA is a voluntary and independent non-governmental organisation uniting medical professionals and patients interested in the prevention and treatment of cardiovascular diseases. LHA educates and informs the public on the prevention of cardiovascular diseases, highlighting risk factors and emphasising the importance of healthy living. The organisation also lobbies for governmental support to improve cardiovascular disease prevention measures in Lithuania.

Read more about the organisation and cardiovascular disease prevention, including a local FH screening programme, <u>here</u>.

New global survey - Women and FH

May 28th marked International Day of Action for Women's Health, a day encouraging organisations and individuals to promote women's health and well-being worldwide. On this occasion, FH Europe partnered with universities and research centres from Norway and the Netherlands to officially launch an international survey on women and FH/HoFH. The aim is to better understand how familial hypercholesterolemia affects women, their family planning decisions as well as health pre-, during and post pregnancy. It is the first project of its kind, initiated in collaboration between a number of research centres and our Network.

Find out more about this exciting project about women and FH here.

Take the survey here and help us reach 1000 women with FH/HoFH internationally.

FH Europe at World Heart Summit

FH Europe was proud to represent patients and people living with inherited lipid conditions causing cardiovascular disease at the World Heart Summit 2022 in Geneva, Switzerland. The 7th edition of the Summit took place on 21-22 May 2022, just two days ahead of the World Health Assembly, under the timely and universal theme of Cardiovascular Health for Everyone. You will find more about the Summit, key presentations and FH Europe's interventions in the June Heart Beat edition.

EAS Annual Congress highlights webinar

The European Atherosclerosis Society 90th Annual Conference took place from May 22nd to 25th in Milan, Italy. This year the patient perspective was shared with the scientific community on three occasions. The international Lp(a) Patient Ambassadors presented their journeys at the EAS FH paediatric symposium, which was recorded in collaboration with FH Europe and thanks to a support from Silence Therapeutics. The event recordings will be available soon. As we work on the congress summary, we wish to invite you to a dedicated webinar on Wednesday, June 15th at 6pm CET covering the congress highlights with expert guest speakers. You can also read some of the highlights directly on the EAS website. Register for the webinar now

New Lp(a) materials available

We are delighted to share that the recently developed support materials for people with elevated Lp(a) are now available on our website. These include a patient support brochure, the latest Lp(a) testing publication and a recording of the Lp(a) Awareness Day launch webinar with a medical expert and Lp(a) patient ambassadors. You'll also find the addition of information on Atherosclerosis dedicated to lipoprotein (a).

Explore the patient support information here

European Commission - EU4Health consultation call

FH Europe has been invited to a Targeted Consultation: EU4Health Priorities, Strategic Orientations and Needs. It is aimed at the European health community, which includes organisations representing patients, civil society, and other parties active in public health and social issues. The consultation is an opportunity for stakeholders such as Healthcare professionals and healthcare providers, researchers, academia and businesses to express their views on current and future EU health priorities. It will discuss strategic orientations and key health needs to be addressed through EU4Health's annual Work Programmes. The consultation will be open until Monday, June 27th 2022.

FH Europe would like to invite interested members of our network to join a special call to discuss the consultation feedback on Tuesday, June 7th at 5pm CET.

Register now to join



Lithuania - CVD risk factors screening

Cardiovascular disease (CVD) is a major cause of premature death in Lithuania. Lithuanian Health Information Centre of the Institute of Hygiene announced that more than a half of all deaths (52,7%) were caused by CVD in 2020. In 2006, a nationwide Lithuanian High Cardiovascular Risk (LitHiR) primary prevention programme was initiated. Every year over 260 000 individuals, without previously diagnosed CVD, are screened. The programme includes evaluation of lipid profiles as well as other CVD risk factors of all those screened. Over 100 000 lipidograms, together with other CVD risk factors have now been analysed.

The findings have led to a National Screening Programme, with dedicated grants for 1000 children (from 5 to 10 years) to be screened for FH.

Read more here.

Hungary - "Green prescription"

Patients in Hungary welcome the green prescription.

A new initiative is being led by Hungary's Mountain Municipality and the SZIVSN patient organisation. One of the pilots for this is Dr. László Lovas, who is now prescribing not only medicine but also exercise on prescription.

"The patients were very receptive to the idea. I hope they will embrace these sessions," comments Dr. László Lovas. Let us know if exercise is being prescribed also in your country to fight cardiovascular disease. Contact info@fheurope.org



European Alliance for Cardiovascular Health - the European Action plan

A European Cardiovascular Health Plan: The need and the ambition

The European Alliance for Cardiovascular Health (EACH), of which FH Europe is a member, revealed its Cardiovascular Health (CVH) Plan for Europe during a high-level policy meeting on May 16th.

This document sets out the ambitious vision of the European Alliance for Cardiovascular Health (EACH) to address the huge burden of cardiovascular disease – Europe's biggest health challenge. It outlines proposals for a dedicated EU Cardiovascular Health Action Plan and Cardiovascular Health (CVH) Mission to commence at the beginning of the next political mandate. The proposals are inspired and informed by the on-going success and impact of the European Beating Cancer Plan and Mission. The EACH CVH plan will have a trickle-down effect with the creation of national CVH plans that are tailored to local contexts and needs.

Read more here, including the Action Plan.

Global Heart Hub

Heart Valves Patient Journey

The Global Heart Hub co-hosted an event in Brussels in April on "Heart Valve Disease in Europe: Creating A Better Patient Journey". This event highlighted the burden of heart disease in Europe and provided an opportunity for attendees to discuss recommendations for a better patient journey.

You can now read the summary report of the event here.

Inspire Speaker Series

This month, Global Hearth Hub's Inspire Speaker Series features Jon Barrick from the Stroke Alliance for Europe (SAFE) discussing "Nurturing Patient Advocacy and Building Sustainable Patient Organisations."

Click here to watch the recording.

EFPIA Cardiovascular Health Report

Towards a new normal: Why boosting CV health is critical. Opportunities for healthcare systems to build back better for patients in Europe.

The European Federation of Pharmaceutical Industries and Associations (EFPIA) CVD Network commissioned a report, in collaboration with PwC, to understand the impact of the pandemic on sixty million CVD patients in Europe. The report calls for screening, outcomes-based care, and data-driven decision making to boost cardiovascular health across Europe. FH Europe, together with a number of other interdisciplinary experts, had an opportunity to contribute, highlighting the need to change the narrative on CVH, to move from the current paradigm (CVD as an effect of lifestyle) to a new approach based on the inclusion of the many determinants of cardiovascular health (CVH), and in particular the genetic and inherited factors.

The report offers a series of concrete recommendations designed to better position European health systems to cope with future crises, putting a huge emphasis on screening and early detection.

You can find out more here, including the report.



- 7 June: European Commission: EU4Health consultation call
- 15 June: EAS Annual Congress highlights webinar
- 27 June 1st July: European Conference on Rare Diseases and Orphan Products

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