



FH Europe Heart Beat News April 2022

Welcome to April's newsletter! Read on for details of the summary of research conducted by FH Europe and the World Heart Federation into the global status of familial hypercholesterolemia (FH) and the reality of people living with FH. Thanks to all those from our community who contributed to this study.

May is a busy month for events and below you'll find details of our guest speaker appearances at the forthcoming EAS Congress organised by the European Atherosclerosis Society (EAS). In partnership with the society, we are offering 5 complimentary registrations to this "must attend" meeting, which explores all the latest developments in atherosclerosis and vascular disease.

Among our network, a new education and awareness project for FH begins in Cyprus to create awareness of and empower women with familial hypercholesterolemia (FH) in Greece and Cyprus. And in Switzerland an FH screening project has been launched.

Also, next month, the European Alliance for Cardiovascular Health (EACH) in collaboration with Friends of Europe, will hold an online debate: Addressing Cardiovascular Health in a Changed and Changing World.

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Results of a global survey into FH advocacy

In 2020, many of you contributed to a survey mapping FH Advocacy efforts in your respective countries. This exercise - conducted in partnership with the World Heart Federation - aimed to present the global status of familial hypercholesterolemia (FH) and the reality of people living with FH and healthcare professionals.

A comprehensive survey was distributed to colleagues from 102 countries in order to map the state of FH around the world. Patients, patient organisations, advocates, physicians, nurses, caregivers, and researchers shared their perceptions and understanding of FH, including prevalence, diagnosis, and treatment of FH in their country, screening strategies and methods of diagnosis, and information on national advocacy efforts.

According to the respondents, **FH remains widely under diagnosed and under treated in all countries and regions.** Fortunately, the responses also suggest that many countries have initiated actions to address FH at a national level. Nonetheless, there is still a long way to go to reduce the global clinical and public health burden of FH.

To read a preliminary analysis and view an interactive summary, please click [here](#).

Cyprus – FH Education for Women

A new education and awareness program for FH begins in Cyprus under the Erasmus+ small scale participation programme. The overarching objective of the project is to educate, create awareness of and empower women with familial hypercholesterolemia (FH),

Created by the Cyprus Atherosclerosis Society, the Hellenic Atherosclerosis Society and the Cyprus University of Technology, the project aims to identify and contact relevant FH patient organisations, identify and shape relevant health education messages for women in Cyprus and Greece and provide educational webinars to health professionals. It will also create health education and communication online tools for the public through a digital and social media campaign.

Follow Cyprus FH on [Facebook](#) to learn more.

Switzerland - The CATCH Study

A new genetic testing project has been launched. It is a multi-centre open-label randomised controlled trial across Switzerland to test whether a cascade screening programme for monogenic or clinical FH, in comparison with usual care, will increase the detection rate of FH within families. It is called the CATCH study. The study includes index cases and their relatives in the French, German, and the Italian part of Switzerland. The CATCH study offers genetic testing for patients with severe hypercholesterolaemia and a familial or personal history of early-onset CVD with a Dutch Lipid Clinic Network score (DLNC) ≥ 6 points.

Read more [here](#).

EAS Congress 2022

Next month, on 22nd to 25th May, the EAS Hybrid Congress takes place in Milan.

Organised by the European Atherosclerosis Society (EAS) - a world leading scientific association - and the Italian Atherosclerosis Society, this will be the 90th EAS Congress. The event can be attended in-person or virtually.

NOW YOU CAN ATTEND TOO!

In partnership with the European Atherosclerosis Society, we are pleased to offer 5 complimentary registration to attend the congress virtually.

Apply [here](#). The deadline is Wednesday, May 11th.

We will be present too.

FH Europe's participation at the event includes:

- EAS Paediatric FH symposium - a satellite session - featuring Magdalena Daccord, who, together with people living with elevated Lp(a), will share patients perspective. If you attend the congress in person, you can register via the website to secure your free spot at the event.
- EAS FHSC Steering Committee Closed Meeting, where FH Europe will share updates on the outcomes of the recent policy activities across Europe.
- WHF Session 2: Global FH – co-chaired by Magdalena Daccord, Chief Executive of FH Europe and Prof Kausik Ray, President of EAS, FH Europe will discuss Changing FH Policy at a European Level. The session will take place on 24th May at 13:30.

For programme and further details visit:

<https://eas-congress.com/2022/>

European Alliance for Cardiovascular Health - virtual event

The European Alliance for Cardiovascular Health (EACH) holds an online debate in collaboration with Friend of Europe next month: Addressing Cardiovascular Health in a Changed and Changing World.

The session takes place on Monday, 16th May 14:00 CEST. The speakers include:

- Stephan Achenbach, Chairman of the Department of Cardiology and Professor of Medicine at the University of Erlangen
- Stella Kyriakides, European Commissioner for Health and Food Safety
- Juozas Olekas, Member of the European Parliament and former Lithuanian health minister

EACH is a unique collaboration representing patients and citizens communities, medical professionals, researchers, health technology providers, the pharmaceutical industry and health insurance associations. FH Europe is a proud member representing its whole Network in this alliance.

You can find out more [here](#).

EURODIS Rare Barometer Survey

EURODIS - the non-governmental patient-driven alliance of rare disease patient organisations - is requesting participants for a study exploring the journey of those who have experience of seeking a diagnosis for a rare disease. The aim is to better identify how to improve the diagnosis journey of people living with rare diseases.

We very much encourage all members and partners of our Network to participate in this survey, which is available in 28 languages and takes no more than 20 minutes to complete and closes on 15 June 2022.

Click [here](#) to take this survey.

The World Heart Federation Summit

Taking place on 21-22 May 2022 in Geneva, the World Heart Federation Summit will bring together world leaders in cardiovascular health under the timely and universal theme of

Cardiovascular Health for Everyone.

Delegates to this exclusive, invitation-only event will engage with policymakers, diplomats, researchers, private sector partners and health advocates, forging ties with leaders and innovators in the global cardiovascular community with the goal of strengthening the global response to cardiovascular disease to help people live longer, healthier lives. The European FH patients community will be represented by Magdalena Daccord, the Chief Executive of FH Europe, as a speaker. Also, Inese Marina from Parsirdi.lv will feature as a speaker at the Summit.

To find out more visit [here](#).

EFPIA – virtual event on cardiovascular health

On Friday, May 15th, the European Federation of Pharmaceutical Industries and Associations (EFPIA) will host a virtual event titled, "Towards a new normal: Why boosting cardiovascular health is critical", to discuss the findings of a report commissioned by the EFPIA CVD Network group. FH Europe has contributed to the report and shared about the importance of early screening and detection of FH and other inherited genetic CVD risk factors like Lp(a) in the process of building a stronger and prevention oriented health system.

More than two years after the COVID-19 pandemic started, healthcare systems are assessing its impact to strengthen their response and improve the health outcomes of patients across disease areas. In this context, EFPIA CVD Network commissioned a report, in collaboration with PwC, to understand the impact of the pandemic on the sixty million CVD patients in Europe.

To join the event register [here](#).

**SAVE THE
DATE**

- **4 - 6 May** – European Stroke Organisation Conference 2022
- **11 May** – EAS complimentary registration deadline
- **15 May** – EFPIA virtual event Towards a new normal: Why boosting cardiovascular health

- **16 May** – The European Alliance for Cardiovascular Health online debate: Addressing Cardiovascular Health in a Changed and Changing World
- **22 - 25 May** – EAS Congress 2022, Milan
- **28 May** – International Day of Action for Women's Health
- **8 June** – Post EAS Congress Webinar
- **27 June - 1 July** – European Conference on Rare Diseases and Orphan Products

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