



FH Europe Heart Beat News August 2022

Today we bring you August's FH Europe newsletter. Although the summer seemed quite, there is a lot to look forward to in September. Important and inspiring events are scheduled to raise awareness of familiar hyperdyslipidemias.

Still this month the biggest cardiology scientific meeting will take place in Barcelona with the latest research and data to be announced. And the international FH advocacy community comes together on three occasions in the upcoming weeks. Among them the meeting in Prague under the Czech EU Presidency followed by a Marketplace event organized by the European Commission.

Both focusing on the FH early screening as a best practice for implementation in prevention of cardiovascular diseases.

Mark your calendars for the next month's FH Awareness Day and World Heart Day. Get involved and start spreading the word!

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Delivering on the mission – FH Paediatric Screening

FH paediatric screening submitted by FH Europe to the European Commission was recognized as an official Best Practice (BP) in 2021 and added to the official [Portal](#).

It was based on the Dutch model with additional Slovenian and Czech models. With the launch of the Healthier Together initiative and record high funding made available for Member States for implementation of health promotion and disease prevention programmes, the focus is on highlighting the [EU Best Practices](#).

EU Best Practice Marketplace event

On September 8 and 9, FH Europe together with scientific experts from the Netherlands and Slovenia will present to the Member States' representatives the FH Screening Programme as an example of a public health Best Practice driving CVD prevention. The programme got selected along with 14 other EU best practices (2 of them are dedicated to stroke). On September 15th the MS will then come together to vote and to select the most relevant BPs to prioritize for implementation and funding from the Healthier Together source. This event is a massive milestone and represent tangible outcomes of a joint multistakeholder collaboration led by patients advocacy community. This is a closed event, by invitation only for Ministries of Health' delegates.

Czech Senate meeting under the auspices of the Czech EU Presidency

Two days prior to the closed event, on September 6, the international advocacy community will come together at the most important, high level event unpacking the barriers and addressing the opportunities in FH paediatric screening implementation. Five expert panels with VIP speakers opening – will address political will, funding, science, health systems, behaviours and trust. Confirmed speakers represent the Czech Ministry of Health, the World Health Organization, the European Commission, the World Heart Federation as well as the European Public Health Alliance, the European Connected Health Alliance,

top scientific experts and patient advocates and many more. This event will produce Prague Declaration and has been endorsed by over 20 organizations.

You are invited to join online or in person. All information including registration can be found on [the official event website](#).

FH Awareness Day

In less than a month, the international FH community will celebrate its awareness day. As the big day falls on Saturday, this year FH Europe will host a special webinar exceptionally on Thursday, September 22. On the day, we will be joined by Prof. Jeanine Roeters van Lennep from the Netherlands and Prof. Kirsten Bjørklund Holven from Norway and international patient ambassadors who will explain how inherited high cholesterol affects women, and how it impacts their cardiovascular health during pregnancy and breastfeeding. This important information can help not only women with FH but also their partners in their joint family planning decisions. This important matter is also the key focus of the recently launched global survey - available in 15 languages thanks to the help of volunteers reviewing the translations. In addition, FH Europe partners with MEDizzy to carry out an international and interactive awareness campaign helping women be better informed about FH.

Register now for the webinar on September 22 and learn more about the exciting campaign we have organized for you. The link is [here](#).

FH Europe Annual Network meeting

Although the in person meeting in Lisbon does not happen until November, we are delighted to announce the satellite webinars prepared for the community with the lead of scientific and medical expert. Get ready and mark your calendars for engaging webinars open to anyone from 6:00 to 7:00pm CET on those dates:

- September 29 – Paediatric Screening – delivering on the mission for people with FH and HoFH
- October 13 – Understanding your lab reports – biochemical vs genetic – for FH, HoFH, Lp(a) and FCS
- October 27 – Lp(a) – all you need to know

- November 2 – FCS a rare lipid condition which requires a strict diet

More information, including registration links, will be shared in September.



NETWORK
NEWS

FHchol Austria

FHchol Austria plans several activities for autumn. It will hold a Regulars' Table on Tuesday, 13th September, with interesting discussions and member networking planned. For more details and to register email: info@fhchol.at or Tel: 0677 63074664.

For FH Awareness Day, they have a stand planned on Thursday, 22nd September 22, at the Mall in Vienna Landstraße, where there will be information and free cholesterol tests.

Since nutrition plays a very important role in FH, they are planning an FH cooking course with an autumnal menu under the banner of "Speed cooking - slow eating", with professional chef Erik Pauer and professional support from dietician Gabriele Skacel. The session takes place on 29th September at the Miele Experience Center Vienna. You can register via info@fhchol.at before 15th September.

And if you can't attend, the cooking course will be documented and published on the FHchol Austria homepage, Facebook page and other social media channels.



PARTNER
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World Heart Foundation Members' Workshop

The World Heart Federation is hosting a Members' Workshop ahead of World Heart Day on 30th August. The theme of the event is "From Global Campaign To Local Impact"

World Heart Day is a global campaign during which individuals, families, communities, decision-makers and organisations around the world participate in activities to take charge of their heart health and that of others. Through this campaign, the World Heart Federation (WHF) unites people from all countries and backgrounds to encourage heart-healthy living across the world.

But adapting all elements of a global campaign so it can reflect the identity, interests, and context of a target audience is not an easy task. During this Meet & Share Workshop, WHF Members from across the globe will explain their World Heart Day activities, campaign goals and expected impact, and how they adapt the WHF's global campaign to meet the needs of their communities.

All info [here](#).

The impact of COVID19 on patients – share your experience

Back in 2020, the **European Patients' Forum (EPF)** the EPF conducted a **COVID-19 survey** between 18 September to 18 October (the report is available [here](#)). It aimed to gather more information on the lived experience and impact of the COVID 19 pandemic on patients and patients' organisations. As the COVID-19 pandemic is not yet over, and it continues to impact the daily life of many patients and patients' organisations, **they have decided to do a follow-up survey**.

This time, the survey is presented as two separate questionnaires. One for patients' organisations (i.e., for you to fill in) and another for **individual patients**.

Ø The **survey for patients' organisations** (in English only) is accessible [here](#).

Ø The **survey for individual patients** (available in **ENG, FRE, GER, ESP and ITA**) is accessible [here](#). To change the language, simply select your preferred one in the top-right corner of the page. In there, the survey can also be switched to "screen reader mode".

The deadline for both these surveys is 25 September at 23.59 (CEST).

Familial Hypercholesterolaemia Australasia Network

The Familial Hypercholesterolaemia Australasia Network (FHAN) is holding its 2022 FH Summit virtually on 1st and 29th October. Both sessions will be online and interactive. Specialists in the areas of cardiovascular medicine, endocrinology and paediatrics, as well as primary care doctors from all over Australia, patients, patient advocates and those working in public health are all welcome to attend.

More information about the FH Summit, including the current programme available [here](#).

Scientific Updates at the European Society of Cardiology congress

All attendees, whether in Barcelona or online, will get the chance to find out from international experts and the industry about the latest ground-breaking research, guidelines as well as lipid lowering therapies and products in the field. Check out the programme here and get ready for post congress announcements. Industry presentations will also be freely available to everyone on [ESC 365](#).

An investigational therapy for FH

Verve Therapeutics, an US based clinical stage company, recently announced the first human dosing with VERVE-101, an investigational base-editing therapy that is designed to treat heterozygous familial hypercholesterolemia. VERVE-101 is the first in vivo base-editing therapy to reach human clinical trials. More will be shared at the upcoming European Society of Cardiology congress in Barcelona.

[Click here](#) to read about this potential therapy on the horizon and the changes it may bring in the future to the lives of individuals with FH if successful in the clinical trials.



SAVE THE
DATE

- **6 September – Hybrid event** addressing the barriers to implementing FH Paediatric Screening in Europe
- **5 - 11 September** - Global Week for Action on NCDs
- **29 September** - World Heart Day
- **29 October** - World Stroke Day
- **4 November** - FCS Awareness Day
- **5 - 6 November** - FH European Network Annual Meeting: Building the Future Together, hybrid meeting online and in Lisbon

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Our mailing address is:

FH Europe

Star House

8 Star Hill

Rochester, Kent ME1 1UX

United Kingdom

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