



FH Europe Heart Beat News

FH Europe Heart Beat News January 2023

Welcome to the January 2023 FH Europe newsletter. A new year means a fresh start while we build on the successes of 2022. And there is already a lot to celebrate. Read on to meet a new FH Europe network's member - Action FCS, learn about the legacy of the Czech EU Presidency in the context of FH paediatric screening. Rare Disease Day is less than one month away - and there are many ways we all can get involved.

Also, find updates from our Network members and their countries, including the launch of the National Cardiovascular Health Plan in Poland with a dedicated action to FH screening. In this edition, we feature updates from Belgium, Czechia, Hungary and Ireland.

Thank you for reading.

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New Year's Message

"I am confident that 2023 will be a year of improved communication and exchange, stronger collaboration and cocreation, support and empowerment through sharing and learning. All of which will help us strengthen our community and drive innovation in how health is valued and preserved, prevention is prioritized, and more personalised patient care and support are delivered. Yet, this will only be possible with your continues engagement, trust and support."

Magdalena Daccord
Chief Executive



Chief Executive´s message for 2023

After a series of successful campaigns and activities in 2022, the coming year will be an interesting one. The FH Europe network can look forward to building on the momentum created through the Lisbon and Prague meetings. 2023 will be marked by structural changes and operational improvements that will improve communications, drive community engagement and ensure FH and FCS make headway when it comes to care as well as policymaking.

Read the address by Magdalena Daccord [here](#).



The Prague Declaration: a lasting legacy of the Czech EU Presidency

FH Paediatric Screening



The legacy of the Czech EU Presidency

Our advocacy efforts have borne outstanding results with the changing of the EU presidency at the start of 2023. The Czech Deputy Prime Minister and Minister of Health, Mr. Vlastimil Válek, has endorsed the Prague Declaration in his official letter to the Swedish Minister for Health Care, Ms. Acko Ankarberg Johansson. This letter draws attention to the FH issue and paves the way for creating a framework for implementing FH Paediatric Screening across the European Union in the future. This incredible advocacy achievement is the result of hard work of Czech and international experts and ambassadors. Congratulations and thank you.

Read more about it [here](#).

welcome to the network



Familial
Chylomicronaemia
Syndrome

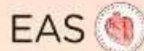


Action FCS joins the network

UK-based Action FCS joined FH Europe Network on 19 January 2023 as its 31st member. With its experience and expertise, Action FCS will improve the support and advocacy efforts for people with familial chylomicronaemia syndrome (FCS). The growing network will more effectively support people suffering from FCS, increase awareness and improve education campaigns to ensure patients' voices are heard by medical and policy audiences.

Read more about Action FCS [here](#).

Visit [Action FCS webpage](#).



**AVAILABLE
TO WATCH NOW**

FCS: Living on Max 20gr of Fat a Day

All you need to know about Familial Chylomicronaemia Syndrome.



First webinar dedicated to FCS

On 19 January 2023, FH Europe partnered with Action FCS and EAS to host a webinar dedicated to Familial chylomicronaemia syndrome (FCS). Entitled, **FCS: Living on Max 20gr of Fat a Day**, the webinar brought together five fantastic speakers who discussed the everyday challenges of the restrictive low-fat diet as well as the science behind the disease and the available therapies. Sufferers and doctors will also get valuable information about how to advocate and raise awareness about FCS and its symptoms in healthcare settings.

Read more about it and watch the recording [here](#).



WE SUPPORT
RARE DISEASE DAY
28 FEBRUARY 2023
#RAREDISEASEDAY RAREDISEASEDAY.ORG

Rare Disease Day coming up

Rare Disease Day is traditionally observed on the last day of February. In the lead-up to this important day, FH Europe has numerous activities and engagements planned to help raise awareness of rare inherited lipid conditions. This year, we will be at the Europe Rare Disease conference in Madrid, Black Pearl Awards in Brussels and more. Read more about how you can participate in the most influential discussions and events focused on rare diseases [here](#).

Find out more about the Rare Disease Day in the EURORDIS section below.

Did you know?

The first Rare Disease Day was coordinated by the European Organisation for Rare Diseases (EURORDIS) and held on February 29, 2008, in numerous European nations and in Canada through the Canadian Organization for Rare Disorders.

The date was chosen because February 29 is the rarest day of the year, but is now celebrated every year on 28th February, and in leap years on 29th.

Belgium - The Belgian Heart League

Living with HoFH – a rare disease Patient Story in French

Marjorie had her first heart attack at the age of 23. Today at 43, she has 8 stents. She suffers from a rare form of familial hypercholesterolemia. With her daughter Aline, she fights the disease every day. **Listen to Marjorie's podcast** (in French) and find out what she needs to do to survive ...

Listen to the whole story on podcast [here](#).

Prepared by The Belgian Heart League

Czechia - Diagnoza FH...

... is now the Czech Alliance for Cardiovascular Diseases (CAKO)

The Diagnoza FH team has now expanded the patients group scope to better serve the needs of cardiovascular disease patients in the Czech Republic and to better promote prevention and cardiovascular health in the country. As a result, Diagnoza FH is now known as the Czech Alliance for Cardiovascular Diseases (CAKO). It is governed by a five-member board, with Zdeňka Cimická as its Chair and Krystina Cillikova as Vice-Chair. Four of the five board members are patients living with FH and HoFH. The new organisation's mission is to continue representing patients with FH and other rare inherited dyslipidaemias. However, CAKO is also open to patients with rare congenital cardiomyopathies, patients recovering from heart attacks, and patients with heart failure. The creation of CAKO was very warmly welcomed in the Czech Republic, where there had not been such an organisation before.

The CAKO website at www.ca-ko.cz will be launched in the coming days.

Prepared by the Czech Alliance for Cardiovascular Diseases

We are delighted about this development and wish CAKO the very best of success in the Czech Republic!

Hungary - SZÍVSN Heartily Hungary

An active beginning of the year

The Hungarian patients' organisation kicked off the new year with an event hosting their ambassador, mountaineer Szilárd Suhajda. As a follow-up, they created a special Facebook group for nutrition education called "Let's eat HEARTLY!". There, you can find information on what to eat, how to shop, and how to prepare meals in the healthiest and fastest way. The group's mission is to share both theoretical research and practical dietary tips based on international research and aimed at preventing heart disease. You can join the group here (in Hungarian):

<https://www.facebook.com/groups/1175271079738941/>

Also, on 27 January 2023, SZÍVSN Heartily Hungary hosted the 15th Heart Failure Congress. Interested parties were invited to the cardiomyopathy patient day, which ran in parallel to the main event and featured educational lectures for patients about heart muscle diseases.

Read more about our campaign and events [here](#).

Prepared by SZÍVSN Heartily Hungary

Ireland - Croí

Advancing a Prevention Agenda for Cardiovascular Care in Ireland

Over the last year, Croí were delighted to be a partner in a research project, commissioned by the National CVD Prevention Council, which culminated in a National Position Paper – **'Advancing a Prevention Agenda for Cardiovascular Care in Ireland'**

This position paper was developed to identify and drive the healthcare policy changes needed to improve prevention and management of cardiovascular disease in Ireland.

Croí as a signatory to the Prague Declaration is encouraged that this paper specifically identifies the urgent need for a National FH Screening Programme. This paper will be officially launched late next month so watch this space as we aim to advance the prospect of FH Paediatric screening here in Ireland!

Prepared by Croi Ireland

Poland - EcoSerce

Launch of the Heart Failure (HF) Patient & Caregiver Charter

Following a conference in October 2022, EcoSerce has successfully launched a Polish version of the Global Heart Hub Patient/Caregiver Charter, which outlines a set of expectations and responsibilities to support the creation and implementation of an internationally accepted standard of care for individuals living with heart failure (HF) and their caregivers. The overall goal of this charter is to support the development of optimal high-quality care and to promote its adoption internationally across all healthcare systems.

This landmark white paper received positive support in Poland. [Read more \(in Polish\):](#)

1. [Article 1](#)
2. [Article 2](#)
3. [Article 3](#)

More in English can be found here: [HFPatientCharter - Global Heart Hub](#).

Prepared by EcoSerce

Polish Government Launches National Cardiovascular Health Plan

On 27 December 2022, **the Polish Government** announced its National Cardiovascular Health Plan on, which budgets EUR 58 million for the period 2023-2032 for 5 key areas of focus and investment in human resources: education; prevention and lifestyle; the patient; science and innovation; and cardiac care system. The work package dedicated to patients specifically names activities dedicated to FH screening.

We welcome the joint announcement by the Polish Lipid Society, led by FH Europe's scientific advisor, Prof. Maciej Banach, and the Polish Cardiovascular Society marking 2023 as the Year of Fighting Hypercholesterolemia. With this step, **Poland is setting an example for other EU Member States to follow!**

The logo consists of a red rectangular background. The words "PARTNER" and "NEWS" are written in white, uppercase, sans-serif font. "PARTNER" is positioned above "NEWS". A thin white horizontal line is located below the word "NEWS".

EURORDIS

Rare Disease Day - show your colours

RDD is a globally coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for those living with a rare disease. Although Rare

Disease Day is patient-led, everyone, including individuals, families, caregivers, healthcare professionals, researchers, clinicians, policy makers, industry representatives and the general public, can participate in raising awareness and taking action today for this vulnerable population that requires immediate and urgent attention.

Learn more how to get involved and raise awareness of inherited lipid conditions [here](#).

Launch of an E-learning event planning tool for under-resourced associations

EURORDIS Open Academy & Events Director, Sharon Ashton-Sirot, launched a new on-demand eLearning course aimed at helping small to medium sized associations and non-profits with limited resources to design and deliver interactive and impactful events while helping save precious time, energy and resources along the way.

Read more about it [here](#).

Enter the eLearning Course [here](#).

The Global Heart Hub

Empower Webinar - How Patients Can Advocate for Themselves with Clinicians

On January 24, The Global Heart Hub launched their new 'Empower' webinar series. These quarterly, patient-focused webinars aim to present up-to-date information, answer burning questions, and communicate in patient-friendly language.

The first session presented The Mended Hearts® 'Seven Steps to Becoming an Empowered Patient' and featured a discussion with three patient advocates on their experiences and practical tips for how to strengthen the patient voice.

[Learn more](#) and [watch the recording](#).

The Global Heart Hub Cholesterol Action Plan: Building successful alliances

Atherosclerotic cardiovascular disease (ASCVD) accounts for 85% of all cardiovascular-related deaths. A major risk factor for ASCVD is low-density lipoprotein (LDL) cholesterol, usually referred to as “bad cholesterol”.

Join our Chief Executive Magdalena Daccord and our scientific and policy advisor Professor Urh Groselj along with Dr Shaun Goodman and Fernanda de Carvalho at this expert panel discussion, moderated by Neil Johnson to hear how our community hopes to affect change in the way unhealthy cholesterol levels are prevented and managed to reduce ASCVD through the implementation of its Global Cholesterol Action Plan. You can tune in live on [LinkedIn](#) on 1 February at 6:00 pm CET. This event and the Invisible Nation program have been created by Global Heart Hub in partnership with Novartis Pharma AG.

Industry news

Amryt Pharma to be acquired by Chiesi Farmaceutici S.P.A

This information concerns patients with HoFH, who are on the lomitapide treatment (known also under the trade name ‘Lojuxta’). On 8 January 2023, Chiesi Farmaceutici S.P.A. and Amryt Pharma Plc announced the companies have entered into a definitive agreement under which Chiesi will acquire Amryt. FH Europe has been reassured that the business decision will not affect the treatment availability for existing patients on lomitopide.

Read the press release [here](#).

SAVE THE
DATE

- 21 February – [EURORDIS Black Pearl Awards](#), Brussels
 - 28 February – [Rare disease Day](#)
 - 15 March 2023 – [Europe Rare Disease Summit 2023](#), Madrid
 - 15 - 18 March 2023 – [RE\(ACT\) Congress and IRDiRC Conference](#), Berlin
 - 24 March 2023 – Lp(a) Awareness Day
 - 24 - 26 March 2023 – [ESC Acute Cardiovascular Care 2023 congress](#), Marseille
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