



## FH Europe Heart Beat News November 2022

Welcome to the November FH Europe Newsletter. This month has been packed with several milestone events. We finally got to meet in person at the Annual Network Meeting in Lisbon. There we discussed the importance of Prague Declaration for FH child screening in Europe and launched the FH Europe Ambassadors Programme. International advocates came together at the European Parliament in Brussels, where our youngest FH Ambassador spoke during the *Taking the Pulse: A Cardiovascular Health Plan for Europe* event. One more cause for celebration is the recognition of another FH Patient Ambassador for their excellent work in Scotland.

We are delighted to report on some significant developments in the field of FH screening in Croatia, access to therapies in Norway and a novel therapy for HoFH. Read about the latest from Austria, Portugal, and the UK.

Our network is growing. We're welcoming a new member from Poland – EcoSerce. Also,

this month learn about our Educational Partner – MEDizzy.

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## FH Europe's Annual Network Meeting 2022

**FH Europe's Annual Network Meeting** took place in Lisbon, Portugal, over the weekend of the 5 and 6 November. The event brought together almost 70 participants for the first time in 3 years, where patient organizations' leaders, individual patients, scientist, clinicians, and policy makers from Europe and beyond had the chance to share, learn and build the future of FH Europe community together.

To find out what made the meeting so special and to check out the photos click [here](#).

### **Thank you**

*FH Europe would like to acknowledge and thank its donors and industry sponsors. The FH Europe Annual meeting 2022 in Lisbon was made possible thanks to the grant from the European Atherosclerosis Society and sponsorships from Amryt Pharma, Novartis, Silence Therapeutics, and Ultragenyx.*

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## **EcoSerce from Poland joins the Network**

We are delighted to welcome **EcoSerce from Poland as the 30th member of our Network.**

The National Association of Patients with Heart and Vascular Diseases EcoSerce is a Poland-wide organization founded by and for cardiac patients and their families. The EcoSerce Association was established in November 2018, but the leaders of the organization have been working for cardiac patients for many years, keeping an eye on the developments in the Polish healthcare system and reacting to them accordingly.

The Association's principal objectives include advocating for the well-being of cardiac patients and raising public awareness of patients' rights as well as fighting for clean air, which is extremely important for those who suffer from heart and circulatory system diseases.

Read more [here](#).

Also in Polish [here](#).

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## New generation learning and awareness raising experience

FH Europe is thrilled to officially partner with [MEDizzy](#), the fastest growing global medical learning community. In its quest to raise awareness and educate about FH and other serious inherited lipid conditions, FH Europe's choice to connect with a young and dynamic community of healthcare professional and medical students is clear.

Read more about this exciting partnership [here](#).

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## Familial Chylomicronaemia Syndrome (FCS) Awareness Day

On 4 November we observed Familial Chylomicronaemia Syndrome Awareness Day.

FCS, similarly to HoFH, is a rare genetic lipid disorder. It is called “familial chylomicron – aemia” because it is inherited through families and the condition results in high levels of chylomicrons in the blood. The degree of elevation of chylomicrons and triglycerides corresponds with the severity of the symptoms.

***Did you know that even a little fat can make someone with FCS seriously ill?***

You can read more [here](#).

Following the participation of **Jill Prawer**, Founder and Chair of [Action FCS](#), and a person living with the syndrome, at the FH Europe annual meeting as one of the guest speakers, we are pleased to share that FH Europe is exploring ways to collaborate closer with the UK charity for people affected by Familial Chylomicronaemia Syndrome. As we progress, we

will keep you posted. Please note that the FCS dedicated webinar will take place in January 2023 with Jill as one of the speakers.

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## Taking the Pulse: A Cardiovascular Health Plan for Europe

Another milestone event is behind us. On 17 November, international FH Europe Ambassadors attended “Taking the pulse: A Cardiovascular Health Plan for Europe” event in the European Parliament, organized by the [European Alliance for Cardiovascular Health \(EACH\)](#) and hosted by MEP Tomislav Sokolov.

High level speakers discussed how the EU can act to improve cardiovascular health for all - the 60 million people in Europe suffering from cardiovascular diseases and the millions of people who are living with a cardiovascular disease without being diagnosed. The overall objective was a call for support for an EU Cardiovascular Health Plan launch in 2024. The event was moderated by Nicola Bedlington, FH Europe’s Senior Policy Advisor.

A big thank you to **Indy Bangma from the Netherlands, the youngest FH Ambassador**, for sharing her story and calling on the EU politicians for action!

Click for [here](#) more information from the event!

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## New Therapy on the horizon for patients with HoFH in the UK

We are very keen to share with you the latest updates in the space of new therapies. On 23 November 2022, Beren Therapeutics, P.B.C. (Beren), a biotechnology company, announced that its cutting-edge lead asset, BRN-002, was awarded an Innovation Passport under the

United Kingdom's Innovative Licensing and Access Pathway (ILAP). The treatment is used to reverse atherosclerosis in patients with Homozygous Familial Hypercholesterolemia (HoFH). The ILAP aims to accelerate the time to market for innovative medicines that address the needs of patients with life-threatening or severely disabling diseases.

Our community welcomes this update, although Beren Therapeutics, P.B.C. is currently in [stealth mode](#).

See the full official press release [here](#).

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## FHchol Austria

### **Will host its General Assembly and FH Patient Meeting with a Lecture**

The event will take place on 1 December 2022 from 6:00 p.m. online on Zoom.

In the programme – the General Assembly for FHchol Austria members only, followed by a video recording from a recent FH cooking course and general exchange. Then there will be a special section dedicated to new conventional therapy strategies for FH patients by Dr Michaela Stögerer-Lanzenberger. To finish Karolin Kastowsky-Priglinger and Lena Hanauer will report from the FH Europe Annual Meeting in Lisbon.

Anyone interested can register by 30 November either by sending an e-mail at [info@fhchol.at](mailto:info@fhchol.at) or by calling 0677 63074664. The event will be held in German. The link for joining the call will be sent shortly before the event.

For more information in German visit the FHchol Austria website [here](#).

*Prepared by FHchol Austria*

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## ANHET France

### **French children are not being screened for FH!**

In France, 50,000 children are estimated to have familial hypercholesterolaemia (FH). Most of them have not been detected and are not treated for the condition, even though current treatments can minimise their risk of suffering a cardiovascular event in adulthood. While it is estimated that FH affects between 225,000 and 270,000 people in France, only 5% of them have been diagnosed today.

You can read more in French [here](#).

Part of the nationwide campaign led by Ahnet.f is aiming at raising awareness among general public, medical community and policymakers and politicians in efforts to prevent unnecessary and preventable premature heart attacks and cardiovascular diseases due to FH. The campaign is being spearheaded by the community of FH patients in collaboration with a dedicated PR agency and takes place in parallel with international efforts coordinated by FH Europe to introduce universal paediatric FH screening - similarly to Slovenia, Croatia, Czech Republic.

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## FH Norge

### **Expanding patient access to PCSK9**

Very important updates for FH Patients in Norway. The LDL-C threshold for Norwegian FH patients without CVD has been lowered from 5 mmol/l to 3,5 mmol/l for therapy with PCSK9 inhibitors, and for patients with CVD, it has been lowered from 4 mmol/l to 2.6 mmol/l –

effective as of 1 January 2023. While the threshold remains too high, more patients will now get access to effective cholesterol-lowering treatment.

Read more in Norwegian [here](#).

*Prepared by FH Norge*

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## Heart UK

### Recognising the Work of Patient Ambassadors

On 3 November, HEART UK held a Roundtable at the Scottish Parliament at Holyrood, hosted by MSP Fiona Hyslop. **Patsy Petrie** contributed to this meeting and shared her experience as an **FH patient advocate**.

Although Patsy is HEART UK's only Scottish Ambassador her effort and impact in raising the issue of Familial Hypercholesterolemia – inherited levels of high cholesterol – were so significant that she was awarded the **Volunteer of the Year Award** for her work by HEART UK at the event attended by Public Health Minister Maree Todd.

You can read more [here](#).

### 20th anniversary of the merger to HEART UK

The year 2022 marks the 20th anniversary of the merger between the Family Heart Association (FHA) and the British Hyperlipidaemia Association (BHA), to form HEART UK. Ever since then, their mission has been to prevent early disease and deaths from cholesterol and other blood fat (lipid) conditions in the UK.

A webinar entitled “Cholesterol and blood lipids – empowering you towards effective management” was held on November 2 to mark the occasion. It provided a unique



opportunity to hear from experts in the field of blood lipids and covered a variety of subjects.

Find out more [here](#).

***FH Europe wishes to congratulate HEART UK on this very special occasion and wishes many more years to come!***

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## **Croí Ireland**

### **Invisible Nation – a worldwide movement**

During October, Croí kicked off a new worldwide movement called **Invisible Nation**, aimed at highlighting, and reducing the large number of preventable deaths from the silent, invisible Atherosclerotic Cardiovascular Disease (ASCVD). Croí rolled out a very successful Irish campaign to raise awareness and shine a light on the role of cholesterol in ASCVD. Celebrity Ambassador and Influencer Daithí O Sé's support and life experience along with media appearances by Dr Paddy Barrett, Consultant in Preventative Cardiology, Blackrock Clinic gave the campaign great weight which received extensive publicity:

- **7,262,555 - Total earned media & social media reach**
- **1,300,944 - Total print reach (5 pieces)**
- **3,664,178 - Total online & broadcast reach (8 pieces)**
- **2,297,433 - Social media reach (20 posts)**

Croí, as a signatory to the [Prague Declaration](#) is encouraged by the engagement throughout the campaign with the public, clinicians and policy makers and will build on this in calling for the introduction of FH paediatric screening in Ireland.

*Prepared by Croí*

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## FH Portugal

### Contribution at the Annual Conference of the Plataforma da Saúde em Diálogo “Health: New Paths, a common purpose”

On 27 October, FH Portugal, member of the Plataforma da Saúde em Diálogo, attended the Annual Conference entitled “Health: New Paths, a common purpose”.

At the conference, Saúde em Diálogo platform’s White Book of Associations entitled “Portraits of the New Time” was presented. The book is the result of the collection of testimonies from patient associations registered on the platform.

In their work, the authors of this work show the perspective of Portuguese patient associations whose mission is to represent the most vulnerable members of society in relation to the health system. The book reveals the consequences of the pandemic for this group as well as what they expect from the future of this relationship in view of the lessons learned.

*Prepared by FH Portugal*

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## Croatia to test children for FH

Starting next school year, screening first graders for familial hypercholesterolemia (FH) will be introduced, and Croatia will be among the few leading European countries with an FH Child Screening program, which identifies the increased cardiovascular risk in children as well as their closest relatives.

The launch of the new screening was announced on 27 October in Zagreb at **Use your**

**brain, chose your heart**, a symposium organised by the World Heart Federation and the Croatian Cardiac Society.

It is estimated that around twenty thousand people in Croatia suffer from such a disorder of fat metabolism, and only **one percent** of them are identified.

This makes **screening children** a very important national initiative that will improve the cardiovascular health of many families and save many lives in the foreseeable future. Given that an average of **30,000 children are enrolled** in the first grade of primary school, it is expected that a hundred children per generation could be diagnosed with this disorder.

Read more about it [here](#).

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## The Global Heart Hub

**Don't miss the Global Heart Hub Unite Annual Summit 2022!**

Make sure you take part in the Unite Summit on 29 and 30 November. This online free event will bring together **CVD patients** and patient advocates from across the globe. FH Europe community will be represented by Magdalena Daccord and Marius Geanta. In the programme world-class speakers and a variety of topics:

- “How to” sessions on sustainable fundraising, professionalising patient organisations and achieving political impact;
- Hot topics relating to Cardiovascular Disease, such as the links between heart disease and mental health, and innovations in personalised medicines;

- Disease focus sessions on heart failure, heart valve disease, Cardiomyopathy, women and heart disease and ASCVD.

More information and registration [here](#).

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## EURORDIS

### **Let's make HoFH and FCS visible!**

We can enter the EURORDIS PHOTO AWARD 2023 by submitting a photo by 22 January 2023. This is our opportunity to visually communicate what it means to live with a rare disease like HoFH or FCS and to share our stories with the rare disease community and beyond. The contest is open to all nationalities, ages and diseases. Every year, hundreds of people from all around the world submit their photos, each reflecting the drive of people living with a rare disease.

Read more about the Photo Award [here](#).

We call on you FH Europe Ambassadors, living with a rare condition, to submit your photo! And if you do so – let us know by emailing Špela on [spela@fheurope.org](mailto:spela@fheurope.org) so we can all vote for your pic and make HoFH and FCS visible!

### **Action Plan for Rare Diseases**

On 25-26 October, the Czech government hosted a milestone conference that should take us one step closer to the delivery of a comprehensive, EU-wide rare disease strategy. EURORDIS and its members have been calling for such a European Action Plan for Rare Diseases since it emerged as the main recommendation of the Rare 2030 study in 2021. The Czech Presidency of the Council of the EU – which comes to an end in December 2022 – has been striving to foster a consensus on an Action Plan.

Read more [here](#).

Check out more updates from EURORDIS, including important policy updates and learning opportunities [here](#).

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## European Society for Cardiology and EFPIA

Brussels will host another relevant high-level event dedicated to importance of screening to avoid CVD. The meeting, entitled “*How can we reduce premature and preventable deaths caused by cardiovascular diseases and diabetes? The case for early detection*” will take place on Monday, 12 December 2022.

Cardiovascular diseases and diabetes are leading causes of death globally. In the EU, almost 60 million people are currently living with cardiovascular diseases (CVD) and the mortality rate is relentlessly high. People with diabetes have an increased risk of CVD and even see their life expectancy drastically reduced by 10–14 years. Unfortunately, it is estimated that over 1 in 3 adults live with undiagnosed diabetes and do not receive any treatment, while 20-40% of heart attacks occur in people previously undiagnosed with CVD.

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

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## The Health Policy Partnership (HPP)

**Action statement urges governments to choose a new future for cardiovascular health**

The Health Policy Partnership (HPP) hosted a webinar on November 22nd to launch a new action statement on cardiovascular disease (CVD): *Governments must choose a new future for cardiovascular health*. It consolidates key findings from our Thought Leadership Forum on Cardiovascular Disease project and calls for more effective political leadership and greater investment in the prevention and management of CVD. If you are working on a wider national cardiovascular health plan this can surely be useful. The action statement features two core recommendations for governments:

- Ensure longer and healthier lives for citizens by establishing comprehensive national cardiovascular health plans to reduce CVD-related deaths, illness and disability by one third by 2030, in line with SDG target
- Reduce inequalities and boost social and economic participation

Read more about it [here](#).

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**SAVE THE  
DATE**

- **29-30 November** - Global Heart Hub Unite Annual Summit
  - **12 December** – How can we reduce premature and preventable deaths caused by cardiovascular diseases and diabetes? The case for early detection
  - **22 January 2023** - Due date for submitting photos for the EURORDIS Photo Award 2023
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