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**From:** FH Europe Foundation <info@fheurope.org>  
**Sent:** Tuesday, 30 June 2026 12:40  
Welcome to the June 2026 edition of Heart Beat News



## Heart Beat News

30 June 2026

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While much of Europe is feeling the heat this month, our community certainly hasn't slowed down! From advocacy milestones and research projects to webinars, conferences, and inspiring initiatives led by our members and Ambassadors, June has been full of energy and collaboration. Thank you for being part of this incredible network—we hope you enjoy catching up on this month's highlights and wish you a wonderful summer!

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**FH EUROPE FOUNDATION NEWS**

**Early Screening for Inherited Lipid Disorders: Thank You for Taking Action**

Thank you to everyone who responded to our call to action on early screening for inherited lipid disorders as part of the future EU Cardiovascular Health Checks. Advocacy letters have already been sent in **Austria, Cyprus, Germany, Greece, Ireland, Romania, and the Netherlands**. In the meantime, we welcome the adoption of the **European Parliament's own-initiative report on an EU Cardiovascular Diseases Strategy**, led by rapporteur Romana Jerković, which places prevention at the heart of EU cardiovascular policy. Read more about the latest developments, the next steps, and how you can continue to support this important advocacy effort. **Read more on [our website](#).**

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## HTAi Meeting

Earlier this month FH Europe Foundation participated for the first time in the **HTAi Annual Meeting 2026** in Istanbul, contributing to global discussions on how Health Technology Assessment (HTA) can shape future health systems. Through the [Lp\(a\) International Task Force](#), **Prof. Florian Kronenberg, Prof. Zanfina Ademi, Dr Iñaki Gutiérrez-Ibarluzea, Marc Rijken and Magdalena Daccord** demonstrated how patients, clinicians, researchers, health economists and policymakers can work together to translate evidence into implementation. The meeting reinforced that meaningful patient involvement is essential to building more equitable, prevention-focused and person-centred healthcare systems. **Read more [here](#).**



The graphic features a dark blue background with a starry pattern. At the top left, it reads 'HoFH WEBINAR TRILOGY' in white, with the tagline 'Advancing Knowledge, Care, and Community' below it. The FH Europe Foundation logo is in the top right. The content is organized into three columns, each representing an episode. Each episode title is in red, followed by the topic in white. Below each topic is a red bar containing a calendar icon, the date, and the time. The dates are 16 June 2026, 23 June 2026, and 30 June 2026, all at 5-6 PM CET.

Episode I	Episode II	Episode III
Starting Early: Changing the Future of HoFH	New Frontiers in HoFH: Expanding Treatment Possibilities	Living the HoFH Reality: Through the Lens of Children, Parents and Siblings
16 June 2026 5-6 PM CET	23 June 2026 5-6 PM CET	30 June 2026 5-6 PM CET

## A New Hope: HoFH Webinar Trilogy Concludes Today

As this newsletter reaches your inbox, the final episode of **A New Hope: The Webinar Trilogy** will take place later today (you can still register [here](#) to attend), completing a three-part series exploring early diagnosis, new treatment advances, and the lived experience of people with HoFH.

A heartfelt thank you to all our speakers, moderators, and attendees for making this series such a success. We are especially grateful to **Lucy Barton, Matt Bolz-Johnson, Chyrel Lichaa, Olivia de Graaf, Elsie Evans, Dr Iulia Iatan, Joanna Kacprzak, Rachel Lalor, Athanasios Pallidis, Prof. Amy Peterson, Prof. Frederick Raal, and Prof. Albert Wiegman.**

Missed a session? The full webinar trilogy will soon be available on our [YouTube channel](#).

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## Lp(a) Update 2026

The [Lp\(a\) International Task Force](#) and FHEF were pleased to participate in [Lp\(a\) Update 2026](#) in Munich, organised by the **German Society for Lipidology (DGFL – Lipid-Liga)**. The meeting strengthened collaboration with the German lipid community while bringing together international experts to discuss the latest advances in Lp(a) testing, prevention, health economics and implementation. Highlights included an inspiring opening session featuring **FHEF Ambassadors Tobias Silberzahn and Corinna Zangerl-Falkeis**, keynote presentations from **Prof. Pia Kamstrup, Prof. Florian Kronenberg, Prof. Zanfina Ademi and Prof. Albert Wiegman**, and valuable exchanges with clinicians, nurses, researchers and industry partners. As Europe moves forward with the Safe Hearts Plan and the upcoming Council Recommendation on Cardiovascular Health Checks, the meeting underscored Germany's opportunity to lead one-time Lp(a) testing as part of routine cardiovascular prevention. **Read the [full blog](#)** to learn more about the discussions, collaborations, and key takeaways from Munich.

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## Strengthening our Voice in the Rare Disease Community

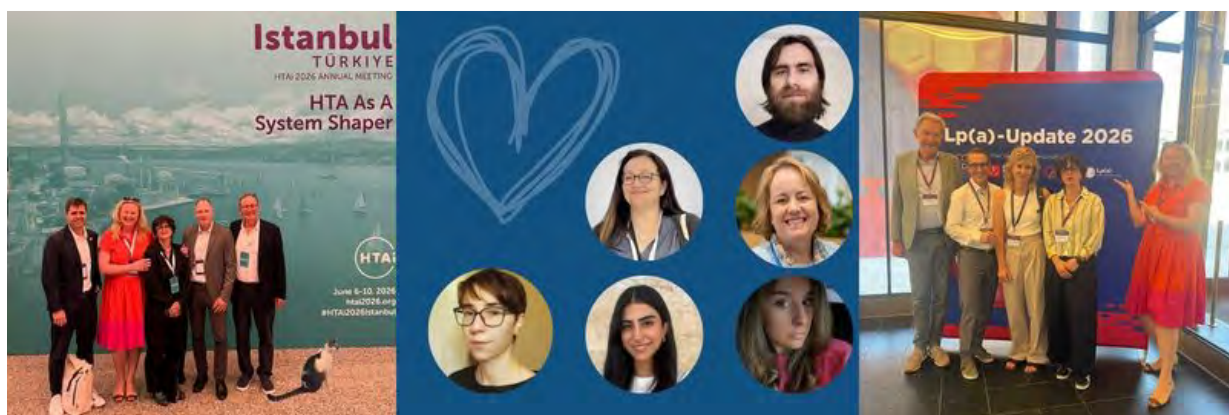
This month marked two important milestones for FHEF's engagement in the rare disease community. We are proud to [have joined Rare Diseases International \(RDI\) as a member](#) and to be [part of the new European Regional Task Force on Rare Diseases](#), led by EURORDIS in collaboration with RDI. These opportunities will strengthen our contribution to **shaping future rare disease policies** while ensuring the voices of people living with rare inherited lipid conditions are represented in European and global discussions on diagnosis, care, research, and equitable access to treatment.

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## Save the Date: FHEF 2026 Annual Network Meeting

Join us in **Dublin, Ireland, from 6–8 November 2026** for the FH Europe Foundation **Annual Network Meeting 2026**, organised in collaboration with **CROÍ**, our local co-host. Taking place during Ireland's Presidency of the Council of the European Union, this year's meeting offers a unique opportunity to strengthen advocacy for inherited lipid disorders at a pivotal moment for European health policy. Bringing together member organisations, patient advocates, healthcare professionals, researchers, and partners, the meeting will feature inspiring discussions, networking, and collaboration. More details on the programme and registration will be shared soon.

## AMBASSADORS NEWS



## Ambassadors at Key Events

FHEF Patient Ambassadors are making their voices heard across Europe and beyond. This month alone, **Marc Rijken** (the Netherlands), **Tobias Silberzahn** (Germany), **Corinna Zangerl-Falkeis** (Austria), **Helga Davidson** (Scotland), **Chyrel Lichaa** (Lebanon), **Athanasios (Thanos) Pallidis** (Greece), **Elsie Evans** (UK/South Africa), **Olivia de Graaf** (the Netherlands) and **Joanna Kacprzak** (Poland) shared their lived experience of Lp(a), HoFH and FCS at two international conferences, an industry meeting and the HoFH Webinar Trilogy. Representing **nine countries**, they joined leading clinicians, researchers and policymakers to help shape research, healthcare and policy while ensuring the patient voice remains at the heart of every conversation. [Read more here.](#)

## RESEARCH PROJECTS

## PERFECTO at the JACARDI WP10 Third Learning Session

PERFECTO was pleased to contribute as an invited **EU4Health Action Grant speaker** at the JACARDI WP10 Third Learning Session in Mérida, Spain. Magdalena Daccord presented how paediatric FH screening supports self-management, prevention, and lifelong cardiovascular health. The session also **strengthened collaboration between PERFECTO and JACARDI**, with discussions on health literacy, citizen empowerment, equity, and sustainable prevention across Europe.



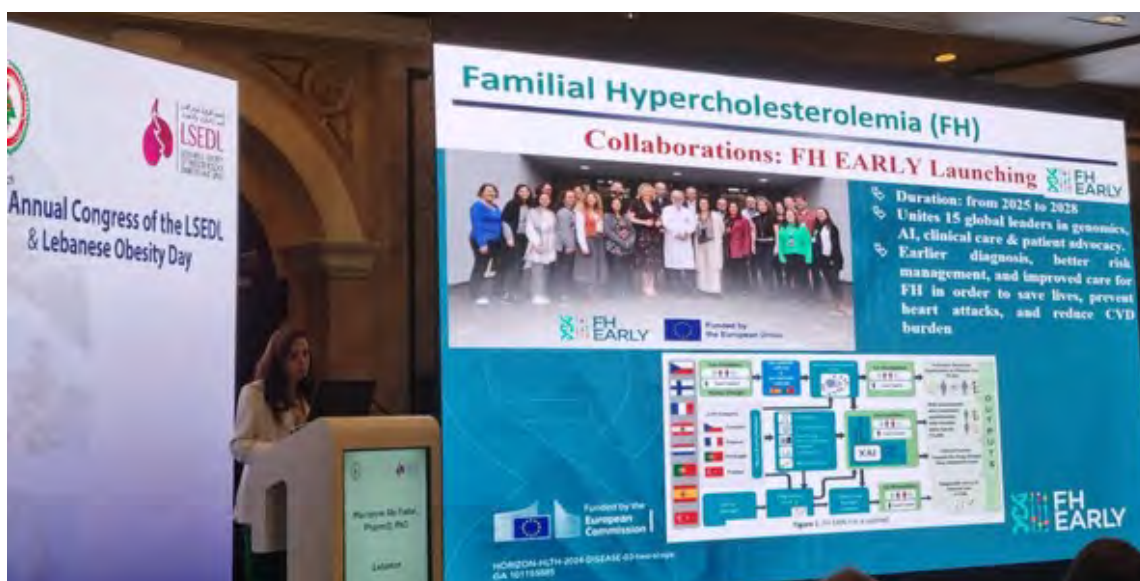
## The Mission to Prevent the Preventable Continues

After 30 months, the EU4Health-funded PERFECTO project has officially concluded, leaving a lasting legacy for paediatric FH screening across Europe. Coordinated by FH Europe Foundation, the project developed practical tools on **personalised communication, health equity, health economics, and patient engagement** to support the implementation of screening programmes. While the project has ended, its mission continues: helping ensure every child can benefit from early diagnosis and lifelong cardiovascular health.

Read more [here](#).



## FH EARLY at the 29th LSEDL Annual Congress



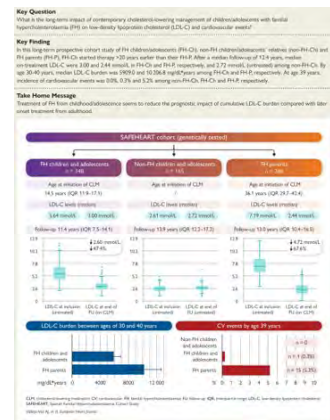
FH EARLY was showcased at the **29th Annual Congress of the Lebanese Society of Endocrinology, Diabetes and Lipids (LSEDL)** in Beirut, where **Prof. Marianne Abi Fadel** presented its objectives during a lecture on FH and PCSK9. The presentation highlighted the importance of improving the early identification and management of FH and helped raise awareness of the project among endocrinologists, lipid specialists, and other healthcare professionals.

## NETWORK NEWS

### Spain: Fundación Hipercolesterolemia Familiar

#### SAFEHEART study

A long-term study coordinated by the Spanish Familial Hypercholesterolemia Foundation through the SAFEHEART cohort found that starting cholesterol-lowering treatment for familial hypercholesterolaemia (FH) in childhood dramatically reduces lifelong LDL-C exposure and lowers cardiovascular risk. By age 39, cardiovascular events occurred in just 0.3% of patients treated from a young age, compared with 5.2% of affected parents who started treatment later in life. These findings reinforce that FH is a paediatric condition requiring early detection and treatment to improve lifelong cardiovascular health and help inform future clinical guidelines and public health strategies. **Full article available [here](#).**



### Latvia: ParSirdi.lv

#### From Innovation to Impact

ParSirdi.lv was proud to contribute to a major initiative advancing the early diagnosis and treatment of FH in Latvia. While led by an outstanding team of clinicians and researchers, including **Professor Gustavs Latkovskis**, the project also demonstrated the **value of meaningful patient organisation involvement**. ParSirdi.lv supported patient education, questionnaires, dissemination, and feedback evaluation. Building on these results, the organisation aims to further

improve FH awareness and diagnosis, while thanking FH Europe Foundation for its ongoing support, guidance and expertise. [Read more here](#).

## Spain: Corazón Sin Fronteras

### Webinar on Women and Cholesterol

How can we improve cholesterol care for women? A recent webinar, led by **Maite San Saturnino Peciña**, explored the findings of the report *Mujer y Colesterol: la realidad de las pacientes*, highlighting the need for earlier detection, coordinated care, equitable access to treatment, and gender-sensitive approaches. A great example of how **multidisciplinary collaboration and patient voices** can drive meaningful change in cardiovascular care.

 Click [here](#) to watch the webinar (in Spanish)

## Singapore:

### FH Connect 2026

*FH Connect 2026: Understanding Familial Hypercholesterolaemia Together* will take place on **5 September 2026 in Singapore**. Organised by **Khoo Teck Puat Hospital** with support from FH Europe Foundation and the **Singapore Heart Foundation**, this free event will bring together people living with FH, their families, and healthcare professionals to learn about the latest developments in FH, share experiences, build community, and connect with experts in a supportive environment.



**FH Connect 2026:**  
Understanding Familial Hypercholesterolemia Together

5<sup>th</sup> September 2026, Saturday 10:00 AM – 1:00 PM

Kaizen 1, Tower B level 1, Khoo Teck Puat Hospital, 90 Yishun Central, Singapore 768828

Let's talk about FH

Register Now!

Scan the QR or Click [here](#)  
No registration fee required!

This event is for individuals living with Familial Hypercholesterolemia (FH) and their family members.

Join us to:

- Learn more about FH from medical experts
- Get your questions answered
- Connect with others in a supportive setting

Lunch provided

Complimentary Gifts (While Stocks Last)

Organised by: Khoo Teck Puat Hospital, FH Europe Foundation, Singapore Heart Foundation

## Czech Republic: ČAKO

### Learning and Prevention in Action

This month, ČAKO showcased two excellent examples of patient engagement and community prevention. On 29 June, the organisation hosted an **online webinar for patients and families**, led by **Dr Martina Vaclová**, covering FH diagnosis, genetics, treatment, and the latest developments

in care. At the same time, with the support of FHEF Ambassador **Kristýna Čillíková**, ČAKO brought prevention directly into the community through its "[Prevention by Bus](#)" initiative, offering cholesterol, blood sugar and blood pressure checks, expert advice, and first aid training. Together, these initiatives demonstrate how education and accessible prevention can improve awareness, promote early detection, and strengthen cardiovascular health.

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## France: Anhet.f

### Webinar - Understanding FH

Yesterday, **Anhet.f** partnered with [IHU ICAN](#) to deliver a webinar dedicated to the genetic risks, diagnosis, and management of FH and Lp(a). Bringing together leading French experts—including **Prof. Sophie Béliard, Dr Antonio Gallo, and Prof. Noël Peretti**—the webinar provided an overview of both heterozygous (HeFH) and homozygous (HoFH) FH, from genetic diagnosis and family screening to the treatment options currently available in France. This collaboration highlights the value of strong partnerships between patient organisations and clinical centres in advancing education, improving awareness, and supporting earlier diagnosis and better care for people living with inherited lipid conditions.

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## PARTNER NEWS

### EURORDIS

#### The Hidden Burden of Living with a Rare Disease: New Evidence Demands Action

Living with rare inherited lipid conditions like HoFH or FCS, is about far more than managing cholesterol or triglyceride levels. New [findings from the EURORDIS Rare Barometer survey](#) reveal that **mental health challenges**, including anxiety, loneliness and emotional distress, are widespread across the rare disease community. For FH Europe Foundation, these findings reinforce a key message from the workshop on the [European Blueprint](#) and the work of the community to drive the Safe Hearts Plan: **holistic care must include mental well-being**. Through our advocacy, Annual Network Meeting mental health sessions, and even 2026 HoFH Awareness Day webinar series, we continue to champion person-centred care that supports both physical and emotional health. **Read more [here](#).**

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### EURORDIS

#### Newborn Screening: Giving Every Child the Best Possible Start

EURORDIS has published a [new position statement](#) calling for stronger and more coordinated newborn screening programmes across Europe. While some rare diseases can be detected at birth and others only later in life, one message is clear: **early diagnosis and timely management are essential to improving long-term health outcomes**. By supporting earlier detection, equitable access, and coordinated care, newborn screening can give children and their families the best possible start while helping reduce inequalities across Europe.

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## Global Heart Hub

### IPEC2 Study Insights

New Global Heart Hub research highlights the unique challenges women face in cardiovascular care. Based on patient experiences from eight countries, the IPEC2 study found that many women delay seeking medical help while prioritising others, contributing to missed or delayed diagnoses despite cardiovascular disease remaining the leading cause of death among women worldwide. The findings call for greater awareness, earlier recognition, and more equitable care for women living with heart disease. **Read more [here](#).**

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## BBMRI-ERIC

### New Resource: European Health Data Space implementation

Our partner BBMRI-ERIC has shared a new Policy White Paper on the **European Health Data Space (EHDS) Implementation in Greece**, outlining recommendations for establishing a national stakeholder ecosystem to support the rollout of the EHDS. The document provides valuable insights into governance, stakeholder engagement, and patient involvement, and may be particularly useful for members involved in EHDS implementation in their own countries. It has also informed discussions around the development of recommendations for the EHDS Citizens Information Point guidelines. **Download the white paper [here](#).**

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## KNOWLEDGE HUB

### EAS

**EAS Paediatric FH Symposium Recordings Available**

The recordings of the **9th EAS Paediatric Familial Hypercholesterolaemia (FH) Symposium** are now available online. Catch up on expert sessions covering screening, diagnosis, new treatment options, dietary management, and the latest advances in paediatric FH care. The programme also featured our CEO, Magdalena Daccord, who shared the patient perspective and highlighted the importance of partnering with families to improve care. **Watch the recordings [here](#).**

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## EUPATI

### Ready for the Next Step in Patient Advocacy?

The **EUPATI Patient Expert Training Programme** offers Ambassadors the opportunity to build advanced knowledge in medicines development, clinical research, and healthcare policy. While the programme requires a significant commitment, it equips patient advocates to contribute as equal partners in shaping the future of healthcare. **Learn more and apply: [Patient Expert Training Programme | EUPATI Open Classroom](#).**

**We also want to celebrate the EUPATI Fellows already in our community!** If you have completed the programme, please send your cohort/year, a short quote, and a photo to [elsie@fheurope.org](mailto:elsie@fheurope.org).

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## Global Heart Hub

### Upcoming Webinar on Cardiac Rehabilitation

Cardiac rehabilitation is a key part of recovery and long-term cardiovascular health, yet many patients still face barriers to accessing these programmes. Join Global Heart Hub's upcoming webinar to explore the patient experience, real-world challenges, and opportunities to improve care. This topic is highly relevant to our community, highlighting the importance of equitable access, long-term support, and patient-centred care across cardiovascular diseases.

**15 July 2026 (5:00 PM CEST): Register [here](#)**

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## EUCAPA

### Build your HTA Knowledge

With the [EU Health Technology Assessment \(HTA\) Regulation](#) now in force, patient involvement in decisions about new medicines and technologies has never been more important. The EUCAPA

Introductory HTA Training is a **free, self-paced, 2-hour online course** designed specifically for patient advocates, covering the fundamentals of HTA, the new EU framework, and opportunities for patient involvement. We encourage all Ambassadors and affiliates to take advantage of this learning opportunity and share your experience with us as we continue building a strong, informed patient advocacy community. **Learn more:** [EUCAPA Introductory HTA Training](#).

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## EMA

### Another Step Forward for the FCS Community

Following its approval by the US FDA, **plozasiran** has now also been approved in the European Union for people living with familial chylomicronaemia syndrome (FCS). Together with last year's approval of **olezarsen**, this reflects growing momentum in the development of new treatment options for this rare disease. Every new approved therapy offers greater hope for patients and families, bringing us closer to more personalised care and improved quality of life.

**Read more about the [earlier US FDA approval in our blog](#).**

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## SAVE THE DATE

- **28-31 August:** [ESC Congress 2026](#), European Society of Cardiology (ESC), Munich, Germany
  - **15 September:** Apheresis Awareness Day
  - **24 September:** [FH Awareness Day](#)
  - **27-28 October:** [World Orphan Drug Congress](#), Amsterdam, The Netherlands
  - **29 September:** [World Heart Day](#), World Heart Federation
  - **6 November:** [FCS Awareness Day](#)
  - **6-8 November:** [FHEF](#) Annual Network Meeting, Dublin, Ireland
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