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Welcome to FH Europe Foundation's November 2024 edition of Heart Beat.

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**FH Europe Foundation**  
The European Familial Hyperlipidaemias Foundation

**Heart Beat News**

## **FH Europe Foundation November 2024 Heart Beat Newsletter**

This month has been a time of important achievements and moments of pride for the FH Europe Foundation. From hosting impactful events to strengthening collaborations, November has truly highlighted the power of our network.

In this edition, we bring you updates from our member organisations in Austria, France, Italy, and the Global Heart Hub, alongside news from our partners and allies. Don't miss the Advent Run in Zagreb, an FH webinar in Dutch by LEEFH, a photo competition by EURORDIS, and much more. We are excited to share with you the truly exciting news from Poland about FH Paediatric Screening.

One of our proudest milestones was our **Annual Network Meeting in Vienna**,

organised in collaboration with FHchol Austria. With nearly 120 participants, the event showcased the exceptional strength of our international community. We were also privileged to honour **Prof. Florian Kronenberg** for his invaluable contributions to the patient community, particularly in addressing elevated Lp(a).

November also marked **FCS Awareness Day**, uniting organisations from the UK, Spain, and the USA to amplify awareness for familial chylomicronaemia syndrome. On the research front, following our engagement with the EP PerMed consortium, we proudly joined **BBMRI-ERIC**, a European biobanking research infrastructure that accelerates the discovery of treatments through robust data and resources.

This month has been pivotal for cardiovascular health advocacy as well. **The European Alliance EACH** led the **Rising to the Challenge** event, highlighting collective goals, followed by the appointment of the new Health Commissioner, who committed to advancing the **CVH Plan for Europe**.

In governance, we welcomed **four new trustees** to our foundation and extended heartfelt thanks to outgoing trustees for their dedicated service.

As we look ahead, December promises to be equally dynamic, beginning with **ISA 2024 in Muscat, Oman**, and the **Global CVCT Forum in Washington, USA**.

Thank you for being part of our journey. We hope you enjoy this month's Heart Beat!



**FH EUROPE FOUNDATION**  
NEWS

FH Europe Foundation

# Annual Network Meeting 2024

8-10 November 2024  
Vienna, Austria



*Together,  
engaged  
for change!*

## FH Europe Foundation Annual Network Meeting 2024: Together Engaged for Change

It was an absolute pleasure to bring together nearly **120 participants**, both in person and online, from **five continents** and **35 countries**. Among our attendees, we were honoured to welcome individuals living with HeFH, elevated Lp(a), and rarer conditions like FCS and HoFH, as well as family members, medical experts, researchers, friends, and our valued industry partners. This collective energy, focused on driving positive change, made the event truly inspiring.

The meeting's theme, "Together Engaged for Change," resonated powerfully throughout the three days. From reconnecting with old friends to forging new relationships, the event fostered collaboration and innovation. The program included thought-provoking debates, inspiring talks, interactive workshops, and meaningful discussions on the future of care for inherited lipid conditions.

We are deeply grateful to our sponsors—Amgen, Arrowhead Pharmaceuticals, Chiesi, Daiichi-Sankyo, Ionis, Menarini Group, Novartis, and Ultragenyx—for their unwavering support. We would also like to thank our local partners, FHchol Austria and the Vienna Convention Bureau, for helping us make the event a success. Your contributions brought our hybrid format to life, allowing us to engage with our global community seamlessly.

The 2024 Annual Network Meeting in Vienna was an unforgettable experience. Thank you to everyone who joined us and contributed to its success. We look forward to continuing our mission together—and we're thrilled to announce that next year, the Annual Network Meeting will be hosted in Zagreb exceptionally on the 3rd weekend of November!

Stay tuned as we prepare a report from the meeting.

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## FCS Awareness Day 2024

On November 1, we marked FCS Awareness Day by coming together with the global community to raise awareness about Familial Chylomicronaemia Syndrome (FCS), a rare and challenging lipid disorder.

For the first time, multiple FCS patient groups—Action FCS (UK), the Spanish FCS Association, the FCS Foundation (USA), and FH Europe Foundation—joined forces to amplify our voices and highlight the under-recognised impact of FCS on patients and their families. This collaboration included the #FCS10gFatChallenge, which invites participants to experience the daily dietary challenge that FCS patients face.

The response has been overwhelming, with many people worldwide—Patient Ambassadors, family members, clinicians, researchers, and advocates—joining the challenge and sharing on social media.

On that special occasion, we released a pre-recorded webinar titled "**Navigating FCS Management**," offering valuable insights into living with FCS and FCS management. Patient ambassador Helga Davidson shared her personal experience of discovering her diagnosis and having to change her life to accommodate the extreme diet in a discussion with Associate Prof. Antonio Gallo, who presented the latest advancements in FCS treatments. The session focused on the critical role of dietary management and the essential support healthcare professionals provide to patients with FCS and their caregivers.

Thank you to everyone who took up the FCS 10-gram fat challenge for one day and helped raise awareness about this very serious rare lipid disorder.

Watch the webinar [here](#).

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## FH Europe Foundation Joins BBMRI-ERIC to Advance Patient-Centric Research

We are proud to announce our membership in the BBMRI-ERIC Stakeholder Forum under the Patients' and Citizens' Pillar. This collaboration aligns with our mission to amplify the voices of those affected by familial hyperlipidaemias (FH, elevated Lp(a), and FCS) and related cardiovascular disorders. By engaging with one of Europe's largest biobanking networks, we aim to advocate for equitable research opportunities, promote patient-centric approaches, and strengthen the study of rare and inherited lipid conditions. Together, we're driving innovation, precision medicine, and personalised prevention to transform cardiovascular health outcomes across Europe.

Learn more about biobanks, BBMRI-ERIC specifically, and how this collaboration has the potential to improve the lives of our community [here](#).



## Advocating for Cardiovascular Health at EACH's Rising to Challenge Event

At the European Alliance for Cardiovascular Health (EACH) event in Brussels, the Rijken family, ambassadors for the FH Europe Foundation, proudly represented patients and caregivers impacted by cardiovascular disease (CVD) and familial hyperlipidaemias. Together, they continue to urge European policymakers to implement a comprehensive Cardiovascular Health (CVH) Plan for Europe, aiming to prevent the preventable and ensure CV health for all.

In 2023, Marc Rijken, alongside his wife Manon and daughters India, Arwen, and Beau, delivered a moving address at the European Parliament, emphasising the urgent need for action to address Europe's overlooked health crisis. A year later, they returned to Brussels, holding policymakers accountable for progress on this vital issue.

The event kicked off with speeches from key stakeholders, including former Health Commissioner and MEP Vytenis Andriukaitis, who highlighted the delay in European legislative initiatives on health determinants such as salt, sugar, and tobacco. Panel discussions with patient advocates, medical experts, and politicians further emphasised the importance of early detection and the need for a holistic CVH Plan.

The Rijken family's ongoing advocacy reinforces that CVD affects not only individuals but entire families. Early detection can prevent the disease, ensuring better health outcomes for generations to come. Together with EACH, the call for a strong CVH Plan continues to gain momentum.

Read a guest blog from our Young Ambassador, India Rijken [here](#).



## Connecting with the International Medical and Research Community: FHEF Ambassadors Attend ISA 2024

In December 2024, Muscat the capital of Oman, will host the 20th International Symposium on Atherosclerosis (ISA 2024), an event convening scientists, in the fight against cardiometabolic diseases. Organized by the Oman Society of Lipid & Atherosclerosis (OSLA) and the International Atherosclerosis Society (IAS), this triennial gathering will run from December 4 to 6 under the theme: “Towards Prevention of Cardiometabolic Diseases through Precision Medicine.”

FH Europe Foundation (FHEF), together with a delegation presenting the voices of patients living with familial hyperlipidaemias, will present nine

abstracts in posters, oral presentations and parallel sessions, covering topics like policy and advocacy, patient support and quality of life, as well as health economics across all 4 disorders (HeFH, HoFH, elevated Lp(a) and FCS).

In addition, FHEF will host a vibrant booth near the Lp(a) testing area, offering resources, sharing insights, and fostering collaboration.

Read more about it [here](#).



## Announcement of Board Transition – Welcoming Our New Trustees

We are excited to announce a significant transition in our governance, with a new group of Trustees joining the Board. We extend our heartfelt thanks to the outgoing Trustees—John Reeves, Giovanni Nisato, Dorota Zgodka, Annelies Dol, and Gergely Jambrik—whose dedication and expertise have been instrumental in FH Europe's growth over the years.

We are thrilled to welcome **Prof. Joanna Lane** as Chair, **Prof. Albert Wiegman** as Secretary, **Dr Ingrid Klingmann**, and **Jan van der Schaaff** as Treasurer. Their leadership and wealth of experience in the health and non-profit sectors will help FH Europe Foundation expand its impact in the fight against familial hyperlipidaemias. Together, with their guidance, we will continue to build a strong global network, focusing on personalised care, research, and advocacy for patients worldwide. This new board marks a pivotal moment in FH Europe Foundation's journey, and we look forward to the future with optimism and determination to create a lasting, positive change in patient and citizen advocacy.

Read more about it [here](#).



## You're PERFECTO

On November 7 in Vienna, the PERFECTO project team held an in-person meeting, bringing together partners to review the first 10 months of the projects, assess the progress, and agree on the next steps. Key highlights included discussions on the progress of two research projects within work packages (WP) 2 and 3 within the PERFECTO initiative, which focuses on integrating social sciences to make FH screening and personalised prevention a reality. These efforts underscore the importance of community engagement and co-creation with those directly affected by FH.

With the results from the international survey looking into FH screening program design, provision, and funding not only across Europe but globally (WP2), the partners agreed that greater involvement of policymakers is required to understand the effective implementation of screening. Furthermore, research surveys (WP3) conducted consecutively in Romania and Cyprus with live focus groups produced some very interesting and new insights into public perceptions, personalised communications models, and public expectations about health care and prevention provision. The partners concluded with the agreement to submit the findings to the upcoming relevant scientific congresses.

The meeting, shouldering with the FH Europe Foundation Annual Network Meeting, featured a special moment with the "Tree of Hearts," where participants were the first to leave their personal messages, symbolising the shared mission of advancing early detection of familial high cholesterol (HeFH and HoFH). in children and young people to prevent premature cardiovascular disease.

Read more about the progress in FH paediatric screening in Poland in the Members section.

Learn more about PERFECTO [here](#).



## **Austria - FHchol**

### **Awareness Activity with Chestnuts in Mariahilferstraße**

Ahead of the FH Europe Foundation Annual Network Meeting 2024, FHchol Austria hosted a unique awareness raising and public engagement activity on Vienna's vibrant Mariahilferstraße, one of the city's busiest shopping streets.

On Friday evening, freshly roasted chestnuts were handed out to passersby along with informative flyers. Chestnuts are a low-fat food rich in beneficial nutrients, making them an ideal choice for those with FH or FCS. During the event, FHchol members shared insights on FH, HoFH, elevated Lp(a), and FCS, engaging the public in meaningful conversations about these important health topics.

We were thrilled to see several FH Europe Foundation international ambassadors join the campaign and actively participate in spreading awareness. It was a fun and impactful event!

A big thank you to SOBI and Ultragenyx for their generous support, which made this activity possible!

*Prepared by FHchol*

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## **France - Anhet.f**

### **Round Table on FH Screening and Treatment**

Yesterday, on November 28, Anhet.f joined a roundtable discussion organised by the French National Academy of Medicine and IHU ICAN. The event focused on cardiometabolic diseases, including familial hypercholesterolaemia

(FH), and aimed to address gaps in screening, treatment, and prevention.

Bringing together researchers, healthcare professionals, patient organisations, and industry leaders, the event explored advancements and challenges in managing these critical conditions.

Anhet.f is proud to contribute to this important dialogue to improve care for individuals affected by FH and related health issues.

*Prepared by Anhet.f*



## Italy - AISC

### AISC APS 2024: Advancing Cardiovascular Research

At the 10th Annual National Conference in Rome on November 9, 2024, AISC APS unveiled research under the theme "Innovation, research, internationalisation: A New Challenge for Managing Cardiovascular Diseases from the Patient's Perspective."

#### Exploring NT-proBNP Testing in General Practice

This study monitored 120 diabetic patients at risk of heart failure, evaluating how SGLT2 inhibitors improved clinical and laboratory outcomes.

#### Empowering Pharmacies in Heart Failure Management

A survey of 281 participants across 50 Italian pharmacies assessed health status and heart failure risk, enhancing pharmacy-led prevention efforts through targeted training.

#### Spreading Awareness with the Mobile Clinic Campaign

This initiative combined education with on-site screenings, measuring glycated haemoglobin and NT-proBNP levels to promote prevention and healthier lifestyles.

#### BIOTOOL-CHF: Personalised Solutions for Heart Failure

A cutting-edge project, still underway, focusing on biomarker-based diagnostics to tailor treatments for congestive heart failure.

Discover more about these impactful projects (in Italian) [here](#).

*Prepared by AISC*



## **Poland- ECO Serce**

### **Prague Declaration leads to FH Paediatric Screening Approval by National HTA**

Exciting news from Poland! The Transparency Council of AOTMiT (Agency for Health Technology Assessment and Tariff System) has issued this month a recommendation to include familial hypercholesterolaemia (FH) screening in routine health check-ups for children aged 5–7. This milestone paves the way for early detection of FH, a significant step in improving cardiovascular health outcomes in Poland.

The breakthrough follows months of dedicated work led by Prof. Małgorzata Myśliwiec and her team, including cost-effectiveness analyses and consultations with healthcare experts and advocates. This success was highlighted during a high-level meeting on Polish cardiology priorities at the Senate in Warsaw on April 11, hosted by Senator Agnieszka Gorgoń-Komor.

Key topics included the importance of systematic FH screening. Agnieszka Wolczenko, President of ECO Serce, presented the Prague Declaration, sparking critical discussions and calls for progress from the Ministry of Health, led by Monika Horna-Cieślak, Ombudsperson for Children's Rights in Poland. FH Europe Foundation was represented by Magdalena Daccord, further emphasising international collaboration. The meeting was closed by Wolczenko, stating, "It is now our priority to follow up on the written position of the MoH on the Prague Declaration as publicly stated in the meeting."

The Transparency Council's position supports the inclusion of "screening for familial hypercholesterolaemia as part of health check-ups" as a guaranteed healthcare service. With Prof. Myśliwiec's long-standing development of a

Polish screening protocol, all eyes are now on the Ministry of Health for the final approval—a formal signature expected soon.

Prof. Mysliwiec from Gdansk, who over the years developed a screening protocol for Polish children, is now expecting the final seal of approval, the signature of the Health Minister, which is expected to happen very soon.

This achievement underscores the power of international advocacy brought to the national level and the collaboration among patient advocates, experts, and policymakers, ensuring early intervention for children at risk of cardiovascular diseases.

Read more about it [here](#).

*Prepared by ECO Serce*



## Global Heart Hub

### Global Heart Hub's 4th Unite Summit Focuses on Living with CVD and Connected Conditions

Global Heart Hub hosted its 4th Unite Patient Summit in Dublin, Ireland, from November 3–5, 2024, welcoming 165 delegates from 34 countries. The Summit brought together leaders from patient organisations, advocates, carers, clinicians, researchers, policymakers, and healthcare stakeholders to address the challenges of living with cardiovascular disease (CVD) and interconnected conditions such as stroke, diabetes, chronic kidney disease, liver disease, and obesity.

Discussions highlighted the lived experiences of individuals managing multiple long-term conditions, innovations in treatment, and actionable priorities to improve patient care and quality of life. The Summit emphasised integrated, holistic care as a solution to fragmented health systems, aiming to strengthen the collective patient voice for policy change.

Global Heart Hub's Executive Director, Neil Johnson, praised the event for fostering collaboration across related communities, advancing patient-centred solutions, and shaping better outcomes for those living with CVD-related conditions.

The Summit featured 20 international speakers and reaffirmed its unique position as a global, patient-led cardiovascular conference.

Read more about it [here](#).

*Prepared by Global Heart Hub*

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## **Croatia - Croatia Dyslipidaemia Patients Association**

### **Running for Awareness: Run4FH at the Zagreb Advent Run**

On Sunday, December 8th, the Croatia Dyslipidaemia Patients Association will participate in the Zagreb Advent Run to raise awareness about familial hypercholesterolaemia (FH).

This year's event is expected to gather over 5,000 runners from Croatia and neighbouring countries. In partnership with the national public health campaigns *Lov na tihog ubojicu (Hunt for the Silent Killer)* and *Znaš li svoj broj? 70/26 (Do You Know Your Number?)*, the run highlights the importance of early detection and action against cardiovascular risks.

The event will be joined by Emma Print, FHEF Community Engagement Manager, reaffirming our collaboration with the Croatian patient organisation ahead of the next Annual Network Meeting.

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## **The Netherlands – LEEFH**

### **Familial Hypercholesterolaemia for (Future) Parents—free webinar**

Join internist **Dr Jeanine Roeters van Lennep** (Erasmus MC) and paediatrician **Dr Willemijn Corpeleijn** (Amsterdam UMC) on Monday,

December 16, 8:00–9:00 PM, as they address key questions for individuals and families navigating familial hypercholesterolaemia (FH), including:

- Should your partner's cholesterol be tested if you have FH and want children?
- Is it safe to take statins during pregnancy?
- At what age can children be tested for FH?
- When should treatment begin for children with FH?

The webinar is organised by **Stichting LEEFH**, **Harteraad**, and **Bert Jan van Veen**, with additional expertise from **De Kinderkliniek's Ineke Bosch**. Don't miss this opportunity to gain valuable insights from leading experts!

Register [here](#).



The banner features the World Patients Alliance logo on the left, which includes a globe icon with people silhouettes. To the right of the logo, the text reads: "WEBINAR Patient Safety Rights Charter DECEMBER 05, 2024 | 9.00 AM ET REGISTER NOW". On the right side of the banner is a grid of 12 small images showing diverse people in various settings. At the bottom right, the website address "www.worldpatientsalliance.org" is displayed.

## World Patient Alliance

### Webinar: Patient Safety Rights Charter

The Patient Safety Rights Charter, endorsed globally and introduced by the World Health Organisation (WHO) in September 2023, sets a framework for safeguarding patient rights and promoting safe healthcare worldwide. Aligned with the Global Patient Safety Action Plan 2021–2030, it emphasises the prevention of harm, equitable access to quality care, and patient empowerment in healthcare decisions.

To explore its significance, the World Patient Alliance (WPA) invites you to a webinar on December 5, 2024, at 09:00 ET. Gain insights into how this Charter strengthens patient rights and advances healthcare safety.

Read more about it and register [here](#).



# EURORDIS

## **EURORDIS Photo Competition – a chance for our community with FCS and HoFH**

The 14th EURORDIS Black Pearl Awards will take place on February 24, 2025, in Brussels, honouring individuals and organisations making a difference in the rare disease community. This hybrid event, open to both in-person and online participation, celebrates exceptional contributions to improving the lives of those affected by rare diseases.

**DON'T MISS IT!** As part of the awards, the **EURORDIS Photo Award 2025 is now open for submissions until January 31, 2025**. This annual contest invites people from all over the world, regardless of nationality, age, or condition, to share their experiences through the lens of photography. Each year, hundreds of compelling images are submitted, offering powerful insights into the challenges, resilience, and humanity of living with a rare disease.

From the entries, award-winning photographer Marcus Bleasdale will select five finalists. Starting February 10, 2025, the public can participate in online voting to decide the winners. The three photos with the most votes will be announced during the Black Pearl Awards ceremony, with the finalists receiving prizes for their impactful stories.

This is a unique opportunity to showcase your story and connect with a global community working together to raise awareness and drive change.

Make your voice heard and submit a photo [here](#).

## **EURORDIS Launched Rare Disease Week 2024 in Brussels**

EURORDIS-Rare Diseases Europe launched the third edition of Rare Disease Week (RDW) on November 18, 2024 in Brussels. The event equipped rare disease advocates with essential skills and networks to amplify their voices in EU policy. RDW 2024 provided a unique opportunity for participants to meet newly elected Members of the European Parliament (MEPs) and EU representatives, ensuring rare diseases remained a priority. The event's hands-on training, EU decision-making simulations, and personal meetings with MEPs were vital in empowering advocates. EURORDIS continued to support patient voices year-round through its Open Academy and advocacy programmes.

Read more about it [here](#).

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# European Patients' Forum

## Ensuring Consistent and Coherent Application of EU Rules on Medicines' Advertising

The European Patients' Forum (EPF) has expressed concern about the fragmented interpretation of current EU rules on the advertising of medicines. Reports from multiple EPF member organisations indicate that this inconsistency leads to unequal access to information for patients across Europe, while also limiting the activities of patient organisations.

As the EU revises its regulatory framework for medicines, EPF urges EU institutions to address the following:

- Establish a clear definition of "patients' organisation" shaped by patients, to formally recognise their central role.
- Clarify that patient organisations are allowed to share factual, balanced information about authorised medicines with patients, in line with applicable legislation.
- Harmonise rules for the attendance of patient experts and healthcare professionals at industry-sponsored conferences and medical congresses, ensuring full compliance with transparency and disclosure requirements.

EPF calls for these changes to ensure equitable access to vital information and support for patient organisations across Europe.

Read more about it [here](#).



# IONIS Pharmaceuticals

## "Core Concepts and Nutritional Strategies" for FCS – free webinar

Ionis Pharmaceuticals extends an invitation to individuals with familial chylomicronaemia syndrome (FCS) to participate in an online presentation that aims to offer valuable information and practical tips for coping with FCS. This Zoom session is open to anyone, whether newly diagnosed or managing FCS long-term. Participants will gain insights into the genetic basis of FCS, its effects on the body, and its role in pancreatitis risks. The session will also explore essential nutritional strategies, including meal planning, FCS-friendly food choices, shopping lists, and easy recipes. Multiple dates are available to accommodate your schedule—click below to register and select the date that works best. Join Ionis to gain tools and resources that support living well with FCS.

Read more about it and register [here](#).

**SAVE  
THE DATE**

- **4-6 December** - International Symposium on Atherosclerosis
- **5 December** – Volunteer Day
- **8 December** – Zagreb Advent Run 2024 (Do You Know Your Number?), Zagreb, Croatia
- **10 December** – Human Rights Day
- **9 – 11 December** – Global CVCT Forum, Washington DC, USA

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