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



FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

FH Europe Foundation December 2024 Heart Beat Newsletter

Welcome to the Final Heart Beat Newsletter of 2024! As we close out the year, we are reflecting on a remarkable December and a year filled with milestones. This month, the European Union made history by prioritizing cardiovascular health, a landmark achievement that bolsters our mission and inspires our efforts.

In this edition, we also revisit memorable moments from the ISA 2024 in Oman, the Global CVCT Forum in Washington and the FH awareness run in Zagreb — each showcasing the growing impact of our network.

A special highlight - we were honoured with the Special Achievement Award from the Croatian Hypertension League for our role in the “HUNT ON SILENT

KILLER” campaign, a shining example of what collaboration can achieve. You will also find updates from our members in Belgium, Croatia, Czechia, Lithuania and the UK, plus highlights from partners like the European Cardiovascular Health Alliance, Global Heart Hub and the World Heart Federation.

Also, this month we launch a new section of the newsletter dedicated to training and knowledge with a focus on the Health Technology Assessment.

To round things off, we’re sharing holiday self-care tips and a little gift—a 2025 Awareness Days and Events calendar!

Enjoy the read, and here’s to a wonderful weekend and a promising new year!



FH EUROPE FOUNDATION
NEWS



Warm Holiday Wishes from FH Europe Foundation

Dear FHEF Network Members, Friends, and Supporters,

As we close out another remarkable year, we want to take a moment to reflect on the progress and impact we’ve made together throughout 2024. Dear Network Members, Ambassadors, your engagement, support and dedication have been at the heart of everything we’ve accomplished, and for that, we are deeply grateful.

As the holiday season unfolds, let’s take this opportunity to focus on what matters most – our health, our well-being, and the cherished moments shared with loved ones. This is a time to celebrate our achievements, express gratitude, and recharge for the exciting possibilities the new year holds.

We also wish to thank our partners and sponsors, who have been supporting us this year in our mission through sponsorships, grants and in-kind donations.

Finally, our gratitude goes to the growing number of volunteers helping us every day deliver the impact our community needs and deserves. Our progress to make the lives of people with familial hypercholesterolaemia better would not be possible without your engagement.

From all of us at FH Europe Foundation, we wish you and your loved ones a joyful, peaceful, and healthy holiday season. May it be filled with warmth, happiness, and a little bit of magic to carry you into 2025 with renewed energy and hope.

We look forward to continuing this journey together in the new year!

With best wishes,
FH Europe Foundation Team



Landmark Council Conclusions on Cardiovascular health

EU Adopts Council Conclusions to Improve Cardiovascular Health

The European Union has adopted the Council Conclusions that mark a major milestone for cardiovascular health advocacy efforts in Europe. They address several key areas related to cardiovascular health, and for the first time familial hypercholesterolaemia (FH), and elevated lipoprotein(a) (Lp(a)) are being referenced to along with cholesterol management, lipid disorders, screening, metabolic inherited conditions, and rare diseases. Here are some highlights relevant to our community:

- FH and elevated Lp(a) are recognized as inherited lipid disorders that often go undiagnosed until advanced disease stages. This delay exacerbates morbidity and mortality due to CVD. The conclusions advocate public awareness campaigns and early detection strategies to

improve outcomes by identifying these conditions sooner and managing them effectively.

- The conclusions highlight the importance of addressing high cholesterol levels as a major metabolic risk factor for CVD and call for the adoption of evidence-based prevention programs targeting modifiable risks, such as elevated cholesterol levels, through lifestyle interventions and pharmacological treatments.
- Member States are encouraged to strengthen cardiovascular health checks to detect early signs of CVD, including lipid metabolism disorders, diabetes, hypertension, and kidney disease. Screening programs should be tailored to diverse population needs, improving early detection and precision diagnostics.
- The conclusions recognize the significant health burden posed by metabolic inherited conditions, including those that affect lipid metabolism and cardiovascular health. Rare cardiovascular diseases, frequently genetic in origin, suffer from delayed diagnosis due to limited medical knowledge and awareness. Enhanced training for healthcare professionals and access to expert networks like European Reference Networks (ERNs) are recommended to address these gaps.

Read more about it [here](#).



FH Europe at ISA 2024: Advocacy and Insights in Action

The 20th International Symposium on Atherosclerosis (ISA 2024) in Oman was a unique platform for the FH Europe Foundation and its ambassadors to raise awareness with record nine accepted abstracts. Taking place every three years, the event brings together global experts in the area of atherosclerosis. This time, hosted by the Oman Society of Lipid & Atherosclerosis (OSLA) and the International Atherosclerosis Society (IAS), the international symposium focused on prevention of cardiometabolic diseases through precision medicine.

For the first time FHEF international patient ambassadors actively participated excelling in various roles, delivering impactful presentations, sharing posters and engaging in various activities at the FH Europe Foundation booth. The booth being very strategically positioned, next to the Lp(a) measuring area, became a hub for many meaningful conversations and offered a backdrop for 19 recorded interviews with international medical experts.

We extend our heartfelt gratitude to everyone who made our participation possible. A special thank you to the IAS for providing us with the booth and awarding three travel grants, to Maxstention for generously producing the booth banners free of charge when our shipments were delayed, and to Arrowhead and Ultragenyx for their invaluable travel grants.

Read more about it [here](#).



FH Europe Foundation at CVCT Washington: Driving Innovation in Clinical Trials

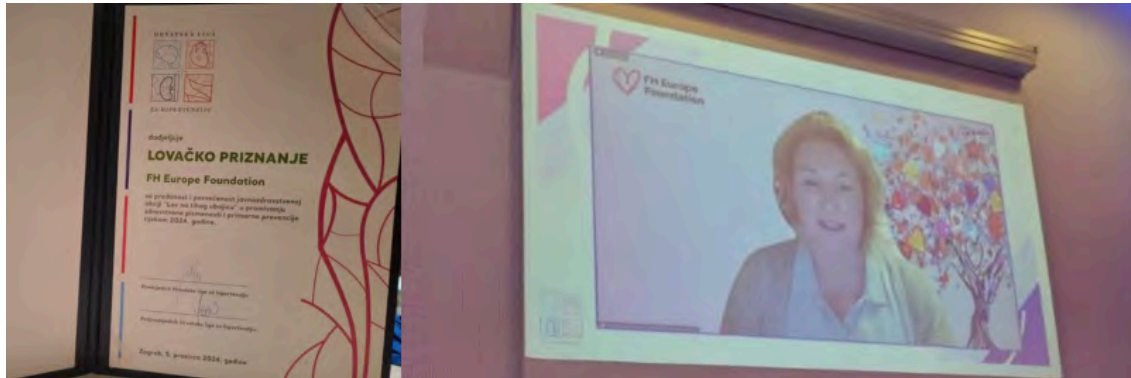
From December 9–11, the CVCT Forum gathered over 400 speakers, incl. 22 international patients and advocates, across 40 sessions in Washington, DC, offering a deep dive into the latest advancements in cardiovascular clinical trials. FH Europe Foundation's CEO, Magdalena Daccord, shared insights on the European Health Data Space and its potential for data-driven research for familial hyperlipidaemias.

The Forum brought together leading trialists, regulators, sponsors, and patient advocates to discuss trial design, implementation, and outcomes. It emphasized inclusivity, expanding its reach to underrepresented regions, and fostered collaboration across disciplines like cardiology, endocrinology, and lipidology.

What stood out? A dedicated session trials in women and women in trials, Artificial Intelligence for trial design, conduct, analysis, & result implementation

and finally a whole track on lipids including trials in cholesterol, HoFH, elevated Lp(a) and FCS.

Read more about it [here](#).



FH Europe Foundation Receives Special Achievement Award

FH Europe Foundation is honoured to receive the Special Achievement Award from the Croatian Hypertension League during their General Assembly. This recognition highlights our cooperation on the impactful “HUNT ON SILENT KILLER” campaign. Our CEO, Magdalena Daccord, accepted the award virtually while attending the ISA2024 meeting in Oman.

Launched five years ago, the campaign is dedicated to raising awareness about the dangers of uncontrolled high blood pressure, cholesterol, familial hypercholesterolaemia (FH), and elevated Lp(a).

We extend our heartfelt thanks to Prof. Dr. Bojan Jelaković, President of the Croatian Society of Hypertension, Prof. Ivan Pećin, and Iva Prgomet from the Croatian Dyslipidaemia Patient Organisation for their partnership and unwavering commitment. Together, we are advancing efforts to improve cardiovascular health across Europe.



FHEF Holiday tips – From our community to you

This holiday season, FH Europe Foundation is sharing the joys of food, physical activity, and mental well-being from and with our community. Throughout the last two weeks of December, we'll post heartwarming stories, tips, and inspirations across these three themes, contributed by our network members, ambassadors, and supporters.

- **Food:** Discover favourite holiday recipes and festive non-alcoholic drinks.
- **Physical Activity:** Explore exercises and workout routines that bring joy and health.
- **Mental Wellbeing:** Learn personal tips for staying mindful and balanced.

Follow us on social media and the hashtags **#BeActive #EatHealthy #SelfCare #FHEFCommunity** to see all the posts and celebrate a healthy, happy holiday season with us by sharing your tips or favourite holiday things in the comments.



Get your Awareness Day and Events Calendar 2025

Embrace the excitement of the upcoming year with the FH Europe Foundation's Events Calendar for 2025! As we gear up for a thrilling year ahead, our dedicated team has prepared this calendar with easy, colour-coded highlights, making it your go-to guide for the exciting events on our radar.

From key **awareness days and events** marked in red, signifying major initiatives and campaigns where your involvement is crucial, to **relevant awareness days and events** in dark blue, encouraging your engagement through likes, shares, and comments for a broader impact. Additionally, discover "**Dates worth knowing about**" in the context of health and well-being, marked in light blue.

[Download the 2025 Events Calendar](#) and be part of the action! Let's make 2025 a year of shared moments, impactful campaigns, and a healthier world. Join us on this exciting journey!

Belgium - Ligue Cardiologique Belge

Championing Heart Health: Join the European Running Championships 2025 in Brussels and Leuven

The Ligue Cardiologique Belge is proud to support the first-ever European Running Championships, taking place on April 12–13, 2025, in Brussels and Leuven. This landmark event welcomes runners of all abilities—whether you're a beginner or a seasoned athlete—to embrace the challenge and promote a healthier lifestyle.

Participants can choose between a 10K or a half marathon, joining over 25,000 runners in a celebration of fitness and community. Organised by Golazo, the Championships are supported by the Ligue Cardiologique Belge and Novartis, the official health partner, to highlight the importance of cardiovascular health.

In addition, eight selected participants focused on heart health will benefit from a 4-month personalised training program with expert coaching, group sessions, and tailored support. Applications close on December 4, 2024.

Read more about it [here](#).



Croatia - The Croatian Dyslipidaemia Patient Association

Zagreb Advent Run 2024: Promoting Public Health and Cardiovascular Awareness

The Zagreb Advent Run, organised by Millenium Promotions and Run Croatia, continues to be a key event in promoting public health in Croatia. This year's race drew over 4,200 participants from across the globe, including Chile, and

garnered significant media attention through national television and radio.

In partnership with the Croatian campaign “Znaš Li Svoj Broj?” (Do You Know Your Number?), part of the “Lov Na Tihog Ubojicu” (Hunt the Silent Killer) initiative, the event emphasised early detection of high cholesterol, high blood pressure, and other cardiovascular risk factors.

Professors Ivan Pećin and Bojan Jelakovic led the campaign, encouraging participants to “know their numbers.” On the evening before the race, runners engaged in proactive health screenings, including cholesterol and blood pressure checks.

The Zagreb Advent Run demonstrates how community events can deliver impactful health messages, combining physical activity with education and screenings. As Professor Pećin declares, “Failure is NOT an option!”—a sentiment that reflects the drive to improve cardiovascular health across Croatia, one step at a time.

Prepared by The Croatian Dyslipidaemia Patient Association



Czechia - ČAKO

Czech Republic Approves National Cardiovascular Plan

At its meeting on Wednesday, December 11, the Czech Government approved an important document, the National Cardiovascular Plan. It defines the necessary changes in the field of cardiovascular prevention and cardiological care in the country that should take place over the next ten years. With this step, the Czech Republic becomes the third country in the European Union, after Spain and Poland, to adopt such a specifically targeted strategic document.

The National Cardiovascular Plan of the Czech Republic for the period 2025-2035 (NCP) was initiated last year by the Czech Society of Cardiology, and other professional societies as well as the patient organisation ČAKO, a

member of FHEF, played an important role in its development. This year, the NCP has been undergoing a comment procedure at the Ministry of Health of the Czech Republic (MoH) and other related ministries and was successfully approved by the MoH on the last day of November. Now its form and mission have also been endorsed by the government.

"This is a very important project because cardiovascular diseases are the most common causes of death, and they are preventable diseases," Health Minister Vlastimil Válek said after the government meeting. While acute cardiovascular care in the Czech Republic is among the world's top performers, the high number of patients, the poor health of the population, and the lack of prevention are another matter, he noted. "That is why the National Cardiovascular Plan puts a major emphasis on preventive measures, and I thank the cardiology society for that," Válek added.

The NCP introduces several notable measures, among the most important of which are:

- Proposals to modernise the physician remuneration system, particularly in the care of high-risk patients or those with CV disease. This could significantly improve their access to care, help reduce long waiting times and ensure timely care where it is most needed.
- Introducing modern methods of prevention, including testing for new risk factors such as lipoprotein(a) concentration and kidney function; introducing digital sharing of laboratory results across the healthcare system; and a national open data centre for cardiac data from the Czech healthcare system;
- Strengthening collaboration between GPs and cardiologists, which is particularly important in regions where access to care is difficult;
- Expanding prescribing options for GPs to improve access to healthcare, particularly in areas with a shortage of specialists.

The NCP has also produced an analytical study summarising key population and clinical data for setting NCP targets and measurable indicators.

By endorsing the NCP, government policymakers are signalling a clear recognition of the challenges in cardiovascular prevention and treatment and expressing a political will for change. Whether these changes actually take place, and the NCP is effectively implemented in the coming years will depend on a number of factors, but above all on the efforts of all governmental and non-governmental actors involved and on securing the necessary funding.

Read more about it [here](#).

HEART UK

Raising Awareness About Elevated Lipoprotein(a) in the UK

FH Europe Foundation's Community Engagement Manager, Emma Print, was recently featured in an article in the Telegraph, UK, which focused on raising awareness about elevated Lipoprotein (a), or Lp(a). This condition affects one in five people yet remains largely unknown to the public and healthcare professionals. Emma, who is an FH Europe Foundation Patient Ambassador, lives with elevated Lp(a) and familial hypercholesterolaemia (FH), both of which are inherited genetic lipid disorders and significant cardiovascular disease risk factors.

Lp(a) levels are genetically determined and remain relatively constant throughout life. However, most general practitioners are unfamiliar with this condition, leading to potential misdiagnoses or overlooked risk factors. Despite the existing guidelines, routine testing for Lp(a) is not standard practice, even for individuals with a family history of heart disease.

Currently, no approved treatments exist to lower Lp(a) levels. Therefore, the management of high Lp(a) focuses on controlling other risk factors, particularly lowering LDL cholesterol levels and hypertension, managing diabetes, and ensuring lifestyle modifications such as a low-fat diet, regular exercise, and smoking cessation. Looking ahead, clinical trials for new medications that could lower Lp(a) levels are underway. These innovative treatments hold the potential to significantly impact the lives of people with elevated Lp(a) and their families by reducing cardiovascular diseases.

The article highlights the critical need for increased awareness of Lp(a) and its role in heart health. FH Europe Foundation is well-positioned to play a vital role in educating both the public and healthcare professionals about this hidden cardiovascular risk factor through the work of the Lp(a) International Taskforce and the incredible Patient Ambassadors.

Read more about it [here](#).

Prepared by Emma Print

Lithuania - The Lithuanian Heart Association (LHA)

Lithuanian Cardiologists Call for Greater Focus on CVD Prevention

This month, associations representing Lithuanian cardiologists issued an open letter to the president, parliament, and newly appointed Cabinet of Ministers, expressing concern over the insufficient focus on cardiovascular disease (CVD) prevention in the government's program. The letter emphasises the urgent need to enhance public awareness, improve access to diagnostic services, and expand prevention initiatives.

According to the Lithuanian Society of Cardiology, over one million lives have been lost to CVD in Lithuania since 2000, with the prevalence of these diseases exceeding the European Union average. This alarming trend underscores the importance of immediate and targeted action.

Prepared by The Lithuanian Heart Association



Global Heart Hub

Global Heart Hub's Manifesto Published in the European Heart Journal

Global Heart Hub's manifesto for early detection and diagnosis of cardiovascular disease has been published in the European Heart Journal. This patient-led manifesto highlights the importance of early action in improving outcomes for those living with CVD.

Developed collaboratively at the GHH Unite Conference in Barcelona, it brought together 125 international patient advocates from 40 cardiovascular organisations, along with clinical leaders, healthcare professionals, and researchers.

Aligned with the latest clinical evidence and real-world patient experiences, the manifesto calls for action to improve health outcomes and ensure the sustainability of health systems.

Read more about it [here](#).

Prepared by Global Heart Hub



Take the Survey: Help Shape the Future of IMD Diagnosis and Management

The Recon4IMD project, supported by UNIAMO, is an ambitious initiative bringing together 34 organizations from 12 European countries, the United Kingdom, and Switzerland. Its mission is to revolutionize the diagnosis and management of inherited metabolic diseases (IMDs).

By collaborating with researchers, clinicians, and patient representatives, Recon4IMD aims to create meaningful and lasting improvements within the IMD community.

Members and supporters are encouraged to contribute to this important project by completing a survey designed to gather experiences related to the diagnosis and management of IMDs.

The insights of patients and caregivers are critical to the success of this initiative, paving the way for a brighter future for those affected by IMDs.

Take the survey [here](#).



European Alliance for Cardiovascular Health (EACH)

Political support for Cardiovascular Health Plan for the EU continues

Following an announcement of the Council Conclusion adoption on December

3, the newly appointed Commissioner for Health and Animal Welfare, Mr Olivér Várhelyi, announced that the European Commission will develop a new European Cardiovascular Health (CVH). Mr Várhelyi reaffirmed his commitment to the development of a new European Cardiovascular Plan, putting cardiovascular health front and centre, just like the Beating Cancer Plan, following the EPSCO adoption of Council Conclusions on the Improvement of Cardiovascular Health in the EU on December 3, 2024.

The success and impact of a European CVH Plan will depend not only on what is achieved in the next few years but on how it is achieved so that no one and no country is left behind. EACH calls on addressing societal barriers, underserved populations, discrimination on all grounds, and fundamental inequities that permeate health systems across Europe. At EACH, we know that the time to act is now.

Read more about it [here](#).

World Heart Federation - WHF

World Universal Health Coverage Day: Bridging the Gap for Cardiovascular Health

On World Universal Health Coverage (UHC) Day, the World Heart Federation highlights the urgent need for governments to act on their commitments to ensure equitable access to cardiovascular care. Despite global pledges, half the world's population still lacks health coverage, and over 2 billion people face financial hardship to afford care.

Cardiovascular disease (CVD), the world's leading cause of death, remains a significant burden, particularly in low- and middle-income countries, where 80% of premature CVD deaths occur.

Ahead of the 2025 UN High-Level Meeting on Non-communicable Diseases, the World Heart Federation calls on governments to adopt strong national CVD action plans, prioritise prevention, improve access to affordable care, and amplify patient voices. Decisive action on UHC is essential to reducing preventable CVD deaths and achieving health for all.

Read more about it [here](#).



We are pleased to launch a new section of the Hert Beat—the FHEF Knowledge Hub! This section will be dedicated to building capacity and sharing knowledge within our community, especially for our FHEF Ambassadors but accessible for everyone who would like to increase their understanding. Each publication will invite you to learn a bit more, with all content also available on our platform.

Keep an eye out for new content, which will include a mix of FHEF-created materials and contributions from others in the wider community. Expect a variety of formats such as webinars, online learning modules, podcasts, whitepapers, quizzes and more. We also encourage you to share any resources you find useful with us. For more information about the Ambassador Programme and training contact Elsie Evans at elsie@fheurope.org.

Our first topic is in line with the changes happening in HTA regulations: Understanding Health Technology Assessment (HTA).

Understanding Health Technology Assessment (HTA)

Welcome to our easy-to-understand training on Health Technology Assessment (HTA). This is the first part of a series that will help you learn about HTA and its impact on the FH Europe Foundation community. Big changes are coming, and this training will help you understand what they mean.

What is HTA?

Health Technology Assessment (HTA) is a way to check if new health treatments are better than the ones we already have. It looks at how well they work, how much they cost, and if they are good for patients and the healthcare system.

Why is HTA Important?

HTA helps decide which treatments should be paid for and available to patients. It makes sure that healthcare money is spent wisely and that patients get the best treatments.

Upcoming Changes in HTA

HTA helps decide which treatments should be paid for and available to patients. It makes sure that healthcare money is spent wisely and that patients get the best treatments.

Starting January 12, 2025, new rules for HTA will start in the EU. These rules will make HTA processes the same across all EU countries. In theory, this will help foster greater collaboration and efficiency, help share information, save time, and make it easier for people, especially those with rare diseases, to get access to innovative treatments faster.

Start your learning journey with understanding the wider concept:

- For a comprehensive introduction to HTA, visit the [Understanding HTA - EUPATI](#).
- To understand the upcoming changes in HTA, check out the [What happens next - overview of changes - EURORDIS](#).

We hope this training helps you grasp the essentials of HTA and prepares you for the upcoming changes. Stay tuned for more instalments that will delve deeper into specific aspects of HTA and their impact on our community over the coming months. If you would like to have the training count towards your Ambassador Journey, please send information to elsie@fheurope.org.



- **February 14** - Europe Rare Disease Summit
- **February 28** – Rare Disease Day
- **March 24** – Lp(a) Awareness Day
- **May 17-18** – World Heart Summit, Switzerland
- **November 14-16** – FH Europe Foundation Annual Meeting, Croatia

Was this email forwarded to you?

Register for your own Heart Beat news [here](#).



Copyright © 2024 FH Europe Foundation, All rights reserved.

You are receiving this email because you opted in via our website or agreed to receive communications at one of our webinars or conferences.

Our mailing address is:

FH Europe Foundation
Printerstraat 22
Amsterdam, 1033RT
Netherlands

Add us to your address book

Want to change how you receive these emails?

You can update your preferences or unsubscribe from this list.

