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



FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

FH Europe Foundation March 2024 Heart Beat News

The first week of spring has been busy with celebrating the Lp(a) awareness day and raising awareness of this important risk factor for cardiovascular disease. Read about Lp(a), the awareness day and all the valuable resources that were provided during the campaign to support the patient and wider community.

Further, mark your calendars on May the 4th, for the first-ever HoFH Awareness Day and join our efforts for unity in HoFH Awareness.

As our efforts expand, our team grows too. We're thrilled to welcome Reante Kaal-Poppelaars as the newest addition to our project team at FH Europe Foundation, joining us as our first volunteer.

Don't miss the latest updates from our Network Members and partners, which include interesting news, events and advocacy projects from Austria, Czech Republic, France, Hungary, UK and globally - from the Global Heart Hub.

With Easter just around the corner, remember to prioritize your health, especially if you have heart or blood vessel conditions. Research by Dr Amany Elshorbagy and the recent PEEK study in Australia highlight the importance of a balanced diet and lifestyle. Stay mindful of what you eat for a healthier heart this season.

Enjoy reading and Happy Easter Everyone!



FH EUROPE FOUNDATION
NEWS

Lp(a) 24th March
AWARENESS DAY



Lp(a) Awareness Day 2024

On Sunday, March 24, we commemorated Lp(a) Awareness Day with a diverse campaign dedicated to shedding light on this crucial topic of a lesser-known yet significant risk factor for cardiovascular diseases. In the weeks preceding the awareness day, our efforts spanned across various platforms, including social media posts translated into **11 languages**, email communications, and an insightful webinar titled 'Ask Me Anything about Lp(a)', where international experts addressed your questions.

The campaign achieved remarkable outreach, supported by the launch of a dedicated website containing essential information and resources about this cardiovascular disease. Moreover, we shared the inspiring patient story of Marc Rijken (featured in our newsletter) and distributed an official press release.

The campaign ended with an important signal sent to the international leaders, policymakers and medical community about the need to measure Lp(a). An Open Letter from The International Lp(a) Task Force calling to “Actively reduce cardiovascular disease burden this Lp(a) Awareness Day” and signed by Members of the **International Lp(a) Task Force** reached many prominent

figures in the space of public health, CVD and prevention with a very positive response so far.

These concerted efforts served to underscore and emphasised the critical importance of raising awareness surrounding elevated Lp(a), thereby highlighting its impact and urgency within the broader health landscape.

Finally, we extend our gratitude to all participants, with special thanks to Novartis and Amgen for their support.

[Read more about it and access the resources](#)

[Read the official press release](#)

[Watch the recording of the webinar](#)



Obesity matters also in people with genetically high cholesterol

On March 4th, we marked World Obesity Day, addressing the profound impact of obesity on cardiovascular health, particularly among individuals with FH, and the critical importance of weight management in reducing the risk of heart disease in this population.

A recent study led by Dr. Amany Elshorbagy on behalf of the [FH Studies Collaboration](#) (FHSC) Investigators delved into the relationship between obesity and cardiovascular disease in FH patients. Findings revealed that over

half of adults and more than a quarter of children with FH globally are overweight or obese. Obesity exacerbates the risk of arterial plaque buildup and atherogenic lipid profile, even with lipid-lowering medication usage. This underscores the urgent need for comprehensive strategies to address obesity alongside cholesterol management, emphasizing lifestyle modifications such as healthy eating habits and regular physical activity to improve cardiovascular outcomes in this population.

Read more about it [here](#).



Renate Kaal-Poppelaars joins the FHEF team

We are excited to welcome Renate Kaal-Poppelaars as our new Project Manager for Internal Processes. With a wealth of experience and a profound personal connection to our cause, Renate has navigated the complexities of inherited lipid disorders within her own family. Another reason to celebrate is the fact that Renate is joining the FH Europe Foundation as our first volunteer in the project team, demonstrating our commitment to building opportunities for volunteers within our operational structures.

Renate's diverse background in project management across various industries makes her an invaluable addition to our team. Inspired by her family's journey with FH and elevated Lp(a), she is deeply committed to health awareness and support. Drawing from both her personal experiences and professional expertise, Renate will play an important role in streamlining our operations and maximizing our impact.

Outside of work, Renate cherishes time with her family and three dogs, embodying her values of connection and balance. She views her involvement

with FH Europe as an opportunity to share experiences and collaborate for improved patient care and outcomes.

We are excited to have Renate on board and eagerly anticipate the valuable contributions she will bring to FH Europe's mission. Join us in extending a warm welcome to Renate as we continue our efforts to make a meaningful difference in the lives of those affected by inherited lipid disorders.

Read more about it [here](#).

One Galaxy, One Heart: UNITY in HoFH AWARENESS

GET READY!



Get ready for the first HoFH Awareness Day!

Get ready to mark your calendars on May the 4th, for the first-ever HoFH Awareness Day! This significant milestone is dedicated to raising awareness about Homozygous Familial Hypercholesterolemia (HoFH), a condition that profoundly impacts individuals and families.

Our upcoming campaign aims to shed light on this condition and its impact on individuals and families, highlighting the importance of early detection and treatment. Stay tuned for further details on how you can actively participate and help spread awareness. We will hold a webinar and launch a social media posts campaign to engage our community in this vital cause. Together, let's unite to make a tangible difference in the lives of those affected by HoFH.

Watch this space for more information!

A promotional banner for a "HealthTech For Patients" event. The banner has a teal and orange geometric background on the left and a photograph of a smiling woman with curly hair on the right. Text on the banner includes: "Patient at the center of innovation", "HealthTech For Patients", "by HealthTech For Care", "May 2024", and "Digital and free event". The "HealthTech For Patients" logo is in the bottom right corner.

"Patient at the center of innovation"

HealthTech For Patients

by HealthTech For Care

May 2024

Digital and free event

The logo for HealthTech For Patients, featuring a stylized orange and teal 'X' shape with a person icon inside, followed by the text "HealthTech For Patients".

HealthTech For Patients Panel will have our HoFH Patient Ambassador

We are thrilled to announce that Maria, our young Patient Ambassador, will be joining the panel at the upcoming HealthTech For Patients (HTFP) event. Hosted by [HealthTech For Care](#), HTFP is a digital and free event scheduled for May 16, 2024.

Maria's participation in this event is a testament to our commitment to amplifying the voices of our community and highlighting the impact of healthcare innovations on individuals. As she shares her insights and experiences, Maria will help bridge the gap between healthcare professionals and patients, ensuring that patient needs remain at the forefront of healthcare innovation.

Stay tuned for updates on Maria's contributions to the panel discussion and how she continues to champion engagement and awareness within our community. Save the date and join us in supporting Maria at the HealthTech For Patients event!

Read more about it [here](#).

NETWORK
NEWS



Austria - FHchol Austria

Gaby Hanauer-Mader Memorial Hike

On Saturday, March 16, 2024, we gathered at the market square in Perchtoldsdorf for a deeply meaningful event: the Gaby Hanauer-Mader Memorial Hike in the picturesque Perchtoldsdorfer Heide. This day was not only about embracing the splendor of nature but also a time to fondly remember our dear Gaby Hanauer-Mader, who holds a special place in our hearts. Alongside members of FH Chol, we were joined by Gaby's close friends as well as esteemed guests, including Nicola Bedlington, accompanied by her husband and Magdalena Daccord. Together, we formed a group of 17 individuals, united in our shared purpose.

Despite the uncertainties of the weather, fortune favored us with brilliant skies as we ventured along the paths of the Heath. Amidst the breathtaking scenery, our conversations flowed freely, interwoven with heartfelt memories of Gaby. Each step was a tribute to her spirit, reminding us of the enduring impact she had on our lives. Following our hike, we sought solace and camaraderie at a nearby wine tavern, where we basked in the warmth of cherished company and reflected on the day's significance.

Our journey led us through the undulating landscapes of the Perchtoldsdorfer Heide, culminating in a well-deserved respite at the Kammersteiner Hütte. Here, amidst the serenity of nature, we paused to replenish our energies and nourish our souls with the bonds of fellowship. As afternoon descended, we reconvened at the Drexler-Leeb wine tavern, where laughter mingled with shared stories and the echoes of Gaby's spirit resonated within each conversation.

To all who contributed to the success of this poignant day, we extend our heartfelt gratitude. Your presence, your stories, and your unwavering support enriched our collective experience, reinforcing the bonds that unite us as members of FH Europe. Together, we honored the memory of Gaby Hanauer-Mader in a manner befitting her legacy, fostering a sense of unity and solidarity that will endure far beyond this cherished occasion.

As we carry forward the spirit of this day, let us continue to embody the values that Gaby exemplified: resilience, compassion, and unwavering dedication to our cause. May her memory continue to inspire us as we navigate the journey ahead, united in our commitment to raising awareness and supporting those affected by familial hypercholesterolemia.

Read more about it [here](#).

Prepared by FHchol Austria

Czech Republic - ČAKO

ČAKO's Milestones: Advocacy to Action

In March, ČAKO advanced significantly in its mission to support patients with rare and inherited cardiovascular diseases and syndromes. Becoming a Supporting Partner of PAGs at [ERN-Guard HEART](#), ČAKO strengthened its ties to the patient community, particularly with two dedicated sites in the Czech Republic serving adult and paediatric patients. This commitment was further evidenced by the launch of "Rare Hearts," a compelling ten-part podcast series featuring leading Czech experts.

Additionally, ČAKO expanded its outreach through participation in the FH Europe Foundation's [Lp\(a\) Awareness Day campaign](#) and embarked on the "[Journey to a Healthy Heart](#)" roundtable series across 13 regional cities. These discussions, involving local healthcare stakeholders, aim to address gaps in cardiac patient care, aligning with the National Cardiovascular Plan objectives. Finally, to empower patients, ČAKO published a practical guide on "[Heart Failure](#)," incorporating the latest recommended practices.

Prepared by ČAKO



France - Ahnet.f

Promoting awareness of FH and the urgency to detect on the big screen

On Tuesday, March 19, the President of the French patient organisation, Lionel Ribas, was invited on the set of ICI 12/13, a daily news programme, on the national France 3 channel. The goal was to talk about FH in the context of health in France and to make the audience in front of TVs watching the programme aware of the disorder as well as the need to screen for it in France

to prevent premature cardiovascular disease. The television intervention comes as part of the wider strategy in the country, led by Anhet.f, to make FH paediatric screening a reality.

You can replay the programme in French [here](#).

Prepared by Afnet.f

Hungary - SZÍVSN

Family doctors signing up for the landmark international study ESCAPE

The international study, ESCAPE, has been launched to provide integrated, patient-centred, psychosocial care to patients over 65 with heart failure and multiple co-morbidities (multimorbid) who are struggling to cope with their illness and its emotional burden.

The National Patient Association SZÍVSN is one of the initiators of the study, because it is monitoring what the patient organisation is working for: the effectiveness of patient education and patient management. They want to assess whether integrated and personalised treatment and patient care improve the coping, physical, and mental health of elderly patients with chronic heart failure and multiple co-morbidities. The ESCAPE project is being implemented as a “Horizon2020” European Union Call for Proposals. The Hungarian partners of the project are the Heart and Vascular Clinic of Semmelweis University and the Institute of Behavioural Sciences.

“Our aim is to see how well these are managed in a coordinated way. During the study, patients will receive additional support from care coordinators, who are nurses with advanced degrees. The care coordinator is in constant contact with the doctors involved in the treatment, ensuring better communication, and providing direct support to help participants work through the problems arising from their illness,” says Zsuzsanna Bernáth-Lukács, president of the SZÍVSN National Patient Association. It can be a problem, due to inadequate information exchange, that a heart patient with multiple chronic conditions visits several doctors’ outpatient clinics.

Read more about it [here](#)

SZÍVSN Continues to Advocate for Cardiovascular Health

In recent weeks, SZÍVSN has been actively engaged in impactful initiatives for heart health. They observed Hypertrophic Cardiomyopathy Awareness Day, emphasizing early detection. Members participated in the AIPM conference, gaining insights into new drug uptake and international studies. SZÍVSN

promoted physical activity through tailored gymnastics sessions and hosted interactive nutrition and heart health sessions. Comprehensive cardiovascular screenings were conducted across Hungary, focusing on early detection. Collaborations with organizations like the Global Heart Hub have expanded SZÍVSN's international reach, reinforcing their commitment to cardiovascular wellness.

Read more about it [here](#).

Prepared by SZÍVSN

UK - Heart UK

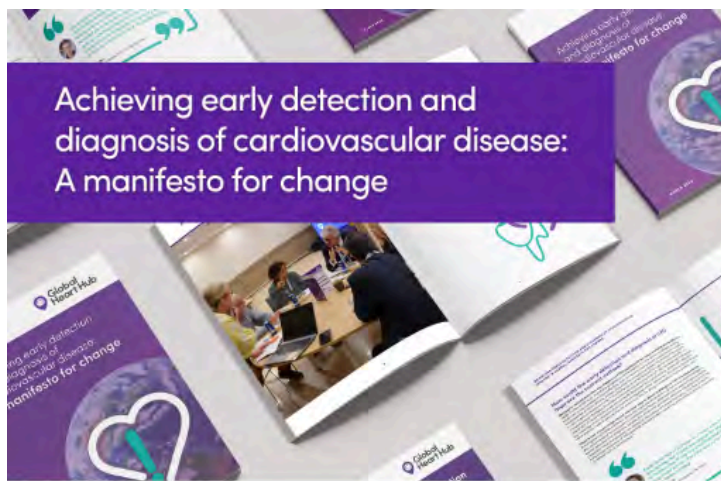
HEART UK launches 'Prevention Pays' analysis

HEART UK has just published a new 'Prevention Pays' analysis. This analysis brings together publicly available data on the number of avoidable CVD events – such as heart attacks and strokes – and the estimated cost of them to the NHS, their national health care provider, to estimate the potential saving to the NHS of reducing them. It also estimates the additional economic gains that could be made by people living longer healthier lives.

This analysis highlights that prevention pays. Investing in measures to prevent avoidable CVD events could help unlock precious NHS resource and provide much needed economic gains. Our findings suggest that savings from increased prevention could theoretically be as high as £2 billion.

The analysis can be read [here](#), alongside a supporting methodology document which is available upon request.

Prepared by Heart UK



 [Learn more](#)



 **Global Heart Hub**

Global Heart Hub

The first patient-led global manifesto calling for early detection and diagnosis of cardiovascular disease is available now, and FH Europe Foundation was delighted to contribute!

Global Heart Hub is delighted to launch the first patient-led global manifesto calling for early detection and diagnosis of cardiovascular disease. “Achieving early detection and diagnosis of cardiovascular disease: A manifesto for change” was developed by Global Heart Hub via a multi-stakeholder approach, bringing together 125 patient advocates including 40 cardiovascular disease patient organisations, key opinion leaders and multidisciplinary experts from across the world.

The landmark manifesto calls on policymakers to implement eight practical evidence-based actions to ensure early detection and diagnosis of cardiovascular disease.

Read more about it [here](#).

Prepared by Global Heart Hub

**PATIENT
STORIES**

*My story
of living with
elevated Lp(a)*



Marc Rijken from the Netherlands

My story of living with elevated Lp(a)

In the spirit of the recent Lp(a) Awareness Day, Marc Rijken, our Patient Ambassador and a dedicated member of the Lp(a) International Task Force, shares his journey battling elevated levels of Lp(a) - a lesser-known yet significant risk factor for cardiovascular diseases. Marc recounts his decade-long struggle, including two heart attacks, before a diagnosis was made. His story underscores the importance of awareness as he educates about Lp(a)'s prevalence and risks, urging proactive measures for individuals with a family history of heart issues. Despite the challenges, Marc finds purpose in advocacy, fostering connections, and promoting knowledge exchange through his ambassadorship. Read Marc's compelling account and gain insights into managing Lp(a) risks for yourself and your loved ones.

Read the full story of Marc [here](#).

PARTNER
NEWS

**Cardiovascular disease
is Europe's biggest killer.**

Consider that when you vote.



#VOTE HEALTH 2024

EACH

The European Alliance for Cardiovascular Health welcomes the EPP's call for a 'European Cardiovascular Health Plan'

The European Alliance for Cardiovascular Health (EACH) applauds the recent initiative by the European People's Party (EPP) to incorporate a 'European Cardiovascular Health Plan' into their electoral agenda. Recognizing cardiovascular disease as the foremost cause of mortality within the EU, the EPP emphasizes the necessity for concerted action to combat this pressing health crisis, which exacts a financial toll of €282 billion annually.

EACH, formed in 2021 to unite patients, healthcare professionals, researchers, and industry representatives, hails this development as a significant stride towards realizing a healthier Europe. The culmination of two years of advocacy efforts, including the impactful Vote Cardiovascular Health 2024 exhibition in the European Parliament, underscores the urgency and relevance of cardiovascular health on the political agenda.

The proposed European Cardiovascular Health Plan, as advocated by EACH, is a comprehensive framework aimed at reducing premature deaths by one-third by 2030, enhancing access to quality risk assessments, and establishing multidisciplinary care pathways. Central to this vision are initiatives such as the European Knowledge Centre and European Cardiovascular Health Check, which align with the broader goal of integrating cardiovascular data and promoting early diagnosis and prevention.

EACH asserts that such a dedicated plan will not only alleviate the burden of cardiovascular disease on individuals but also yield societal and economic benefits. By fostering collaboration and innovation across borders and tailoring interventions to national contexts, the plan holds promise for transforming the landscape of cardiovascular health in Europe.

As echoed by EACH's Patient Representative, achieving these ambitious objectives demands a paradigm shift in stakeholder engagement and a unified commitment to tackling cardiovascular health as never before.

Read more about it [here](#).

EURORDIS

Rare Diseases Addressed at the European Parliament

Rare Disease Day prompted a vital discussion at the European Parliament's SANT Subcommittee on Public Health. Yann le Cam of EURORDIS-Rare Diseases Europe and Danielle Drachmann of Ketotic Hypoglycemia International joined MEPs and European Commission members to advocate for rare disease patients. Le Cam introduced the #ActRare2024 campaign, urging sustained EU prioritization for rare diseases. MEPs stressed the urgency for a robust European strategy and collaborative research framework. They emphasized healthcare sustainability, reducing disparities, and enhancing social inclusion. MEP Kateřina Konečná highlighted the inequality in newborn screening across the EU. Revising the Cross-Border Healthcare Directive is crucial for ensuring access to specialized care. Supporting families, mental health, and social rights are paramount for equitable participation. EURORDIS and the rare disease community await collaborative efforts with policymakers. Drachmann urged actionable legislation, emphasizing the need for prompt policymaker action to alleviate rare disease patient suffering. Tangible actions are imperative to address rare disease challenges effectively.

Read more about it [here](#).

#ActRare2024: What progress must the EU make on rare diseases?

EURORDIS has launched the #ActRare2024 campaign, aiming to influence the June 2024 European Parliament elections and the upcoming European Commission appointments. The campaign seeks to engage policymakers, advocates, and patient organizations to maintain rare diseases as a priority in the EU's 2024-2029 legislative term. Focusing on eight key areas, including the creation of a unified European policy framework for rare diseases, the campaign urges the next EU officials to take concrete actions. One crucial

aspect is earlier, faster, and more accurate diagnosis, addressing the significant wait times for patients. Another priority is integrated national and European healthcare pathways, aiming to ensure fair access to specialized care across the EU. Additionally, the campaign calls for prompt access to affordable and innovative treatments, person-centered holistic care, innovative research and development, optimized health data usage, and sustainable treatment development. With the support of MEPs and stakeholders, EURORDIS aims to establish a European Health Union that prioritizes rare disease patients' needs. Supporters can engage with the campaign using the #ActRare2024 hashtag on social media and contribute to its success.

Read more about it [here](#).

World Heart Federation (WHF)

Dr Pablo Corral Discusses Lp(a) Awareness with the World Heart Federation

In celebration of Lp(a) Awareness Day, the World Heart Federation conducted an illuminating interview with Dr. Pablo Corral, a distinguished expert in the field. Dr. Corral, Past President of the Argentine Lipid Society and an esteemed Internal Medicine Physician and Lipidologist, provided valuable insights into Lp(a), a lipoprotein associated with cardiovascular risks. Highlighting its genetic predisposition, Dr. Corral stressed the importance of regular testing, as lifestyle changes have a limited impact on Lp(a) levels. He recounted professional achievements, including recognition from the Argentine Society of Cardiology for groundbreaking research on Lp(a). Dr. Corral urged healthcare professionals to prioritize Lp(a) testing and advocated for comprehensive coverage by healthcare systems. His message to patients emphasized the significance of understanding their Lp(a) levels and engaging in proactive discussions with healthcare providers. Looking forward, Dr. Corral expressed optimism about forthcoming advancements in treatment options. In conclusion, he emphasized the critical need for individuals to know their Lp(a) levels at least once in their lifetime.

Read more about it [here](#).

WHF Amplifies Awareness for Women's Cardiovascular Health

On International Women's Day, the World Heart Federation (WHF) took a moment to reflect on its efforts in raising awareness about cardiovascular disease (CVD) in women. Despite CVD being the leading cause of death among women globally, misconceptions persist, leading to underdiagnosis and undertreatment. Through social media campaigns and informative videos, WHF

aims to empower women with knowledge about their risk factors and symptoms. Dr. Sanne Peters, a member of the WHF Science Committee, recently discussed common myths and risk factors associated with CVD in women, stressing the importance of early detection and treatment. WHF continues its mission to advocate for better recognition of CVD as a significant health concern for women.

Read more about it [here](#).

European Patients Forum

The European Alliance for Cardiovascular Health welcomes the EPP's call for a 'European Cardiovascular Health Plan'

The European Patients Forum (EPF) is pleased to acknowledge the recent strides made by the European Parliament's ENVI Committee in advancing the revision of EU pharmaceutical legislation. EPF underscores the significance of heightened patient involvement and the implementation of accessibility enhancements within the regulatory framework. These advancements are pivotal in ensuring that patients have a more active role in decision-making processes and are better equipped to access necessary treatments. EPF urges Member States and pharmaceutical companies to ensure that the proposed measures result in tangible benefits for patients throughout the European Union.

Throughout the revision process, EPF has been actively engaged, contributing to discussions and advocating for a patient-centered approach. As the legislative process continues to unfold, EPF remains steadfast in its commitment to working closely with EU institutions to ensure that the new rules prioritize the needs and well-being of patients.

For further insights, read [EPF's comprehensive position paper on pharmaceutical legislation](#).

Empowering Young Patient Ambassadors: A Vision for the Future

In recent months, the EPF Youth Group, alongside our Patient Ambassador, Aedan Kaal, under the European Patients' Forum (EPF), has launched the transformative project "Youth Involvement in Patient Organisations (POS)". This initiative emphasizes integrating young patient advocates into the framework of patient organizations, shaping a more inclusive healthcare landscape.

Their mission is to nurture the skills and confidence of young patients, fostering a more empathetic and dynamic approach to health advocacy, while addressing the expressed desire for youth involvement within patient organizations.

Through extensive research and collaboration, they've developed a free online course for POS leaders, crafted by young patients themselves, to offer crucial insights into effective youth engagement and bridge generational divides in advocacy.

The ultimate goal is to prepare the next generation of leaders in patient advocacy, fostering resilience and vibrancy within organizations worldwide. By championing youth empowerment, they pave the way for a future where every voice is heard, and every perspective valued in the pursuit of equitable healthcare.

Aedan Kaal, FH Europe Foundation's patient ambassador, will continue to provide updates on the progress of this initiative, ensuring our community remains informed and engaged in this vital work.

NEW
PUBLICATIONS

TEN THINGS people diagnosed with heart and blood vessel conditions need you to know and care about

Heart disease and blood vessel conditions affect millions worldwide, impacting physical, emotional, and mental well-being. Despite this widespread impact, there are significant challenges faced by individuals diagnosed with these conditions. A recent comprehensive study, conducted in an Australian population, sheds light on these challenges and provides valuable insights into patient experiences in managing heart disease and blood vessel conditions. The PEEK study offers a deeper understanding of the complexities involved in navigating these health challenges. Its findings, presented in the report, patient and health professional videos, clinical pathway, and decision-maker brief, are available online for further exploration and utilization.

Read the full publication [here](#).

SAVE
THE DATE

- **4 May (NEW!) - HoFH Awareness Day**
- **24-26 May** - World Heart Summit 2024, Switzerland
- **25 May** - 7th EAS Paediatric Familial Hypercholesterolemia Symposium, Lyon, France
- **26-29 May** – EAS Annual Congress, Lyon, France

- **8-10 November** – FHEF Annual Network Meeting 2024
-

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