Welcome to FH Europe Foundation’s June 2024 edition of Heart Beat.

FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

FH Europe Foundation June 2024 Heart Beat Newsletter

Before we dive into summer and turn on vacation mode, we would like to share some important news, as well as our ongoing and future activities and events from our most important projects and our wider community with you.

Our current focus is on the HoFH Awareness Day Logo Competition. We invite you all to help us create a lasting symbol that will represent the HoFH community in the future.

Reflecting on recent events, Elsie Evans represented us at the EURORDIS Open Academy and the European Conference for Rare Diseases and Orphan Products, driving patient advocacy and collaboration.

Looking ahead, mark your calendars for the FH Europe Foundation Annual Network Meeting in Vienna this November, where we will focus on co-creating solutions for the lipid community.

Our delegation will attend a significant cardiovascular disease conference in Hungary, addressing the EU's health agenda. We will also advocate for personalised medicine at the Citizen Engagement Board at EP PerMed, and our patient ambassadors have submitted nine impactful abstracts to the ISA 2024 in Oman, showcasing our community's research and advocacy efforts.

The PERFECTO project, dedicated to early detection of inherited high cholesterol in children, now has a dedicated website and is live on social media.

Finally, join us in celebrating local initiatives, from successful cooking classes for HoFH families, mobile health units, a Healthy Heart Act, and the launch of a FH reverse cascade screening programme to roundtables.

Stay active, stay connected, and stay healthy. Have a wonderful summer!

Share Tweet Share Forward

FH EUROPE FOUNDATION NEWS

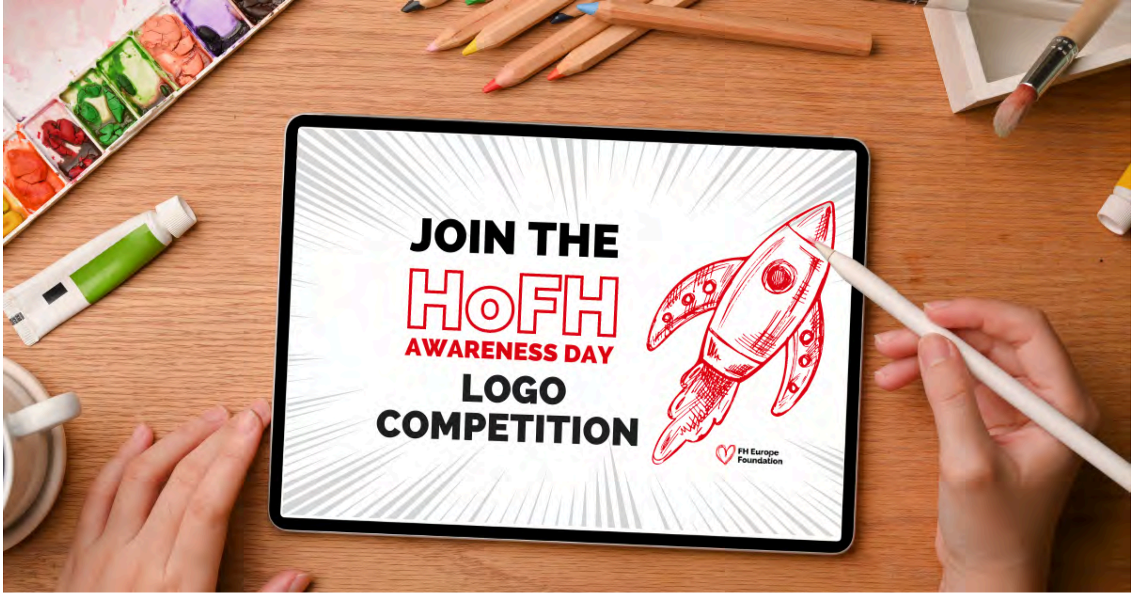
Cardiovascular Disease in Focus at High-level Conference in Hungary

Cardiovascular disease (CVD) remains a critical concern, as highlighted by the European Commission, the European People’s Party (EPP), the European Socialists and Democrats (S&D), and the Greens/EFA.

We are pleased to announce that the FH Europe Foundation has been invited to the High-Level Conference on Cardiovascular Health organised by the upcoming Hungarian Presidency on behalf of Dr Péter Takács, Minister of State for Health of the Ministry of Interior, Hungary . A delegation from FHEF will represent the network of 32 patient organisations and the broader community of individuals with familial lipid disorders and CVD risk factors and will be attending this significant conference in Budapest on July 4th. This event, organised in collaboration with the European Society of Cardiology, will feature Hungary presenting a concept paper on cardiovascular diseases.

The conference will address key issues in prevention, innovation, and treatment, while also considering geographical and gender inequalities. This initiative is particularly crucial, as diseases of the circulatory system are the leading cause of death in the EU, accounting for nearly one-third (32.7%) of all deaths in 2020, according to Eurostat. Notably, Hungary faces a high mortality rate from coronary heart disease.

Read more about it here.

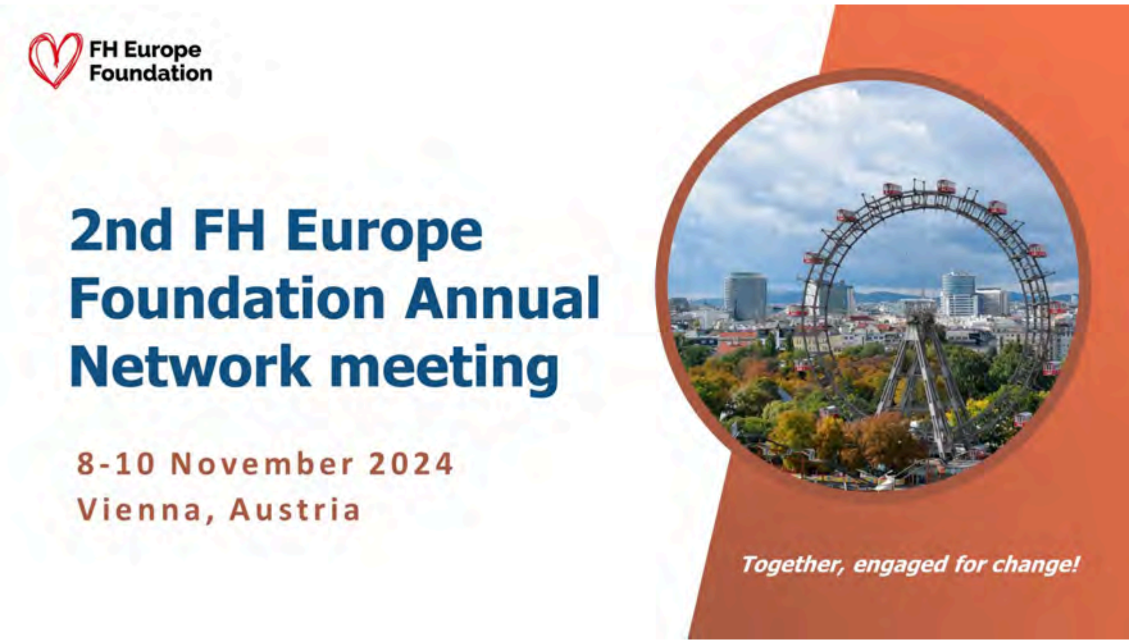


Join the HoFH Awareness Day Logo Competition

Whether you're a seasoned designer or simply passionate about raising awareness or drawing and telling a good story with your art, this is your unique chance to be part of something very special.

The purpose of the **HoFH Awareness Day logo** is to have a global visual, an image that will **represent and unite the HoFH community** now and for years to come.

For more information, visit the Logo Competition Webpage, meet the judges, and mark the due date to submit your visual: 24 September 2024 (FH Awareness Day).



FHEF Annual Network Meeting 2024: Together, engaged for change

We are pleased to announce that this year's Annual Network Meeting will kick off with 4 dedicated webinars from October 3rd (Thursday), followed by a face-to-face meeting from **8 to 10 November in Vienna, Austria**.

Bringing together the FH Europe Foundation´s community, this year's event will blend tradition with fresh, relevant content, focusing on co-creating solutions to critical challenges within the lipid community. Attendees will have the opportunity to strengthen connections, reflect on shared learnings, and strategize future goals, all while celebrating community successes.

The event will consist of two parts: the four pre-meeting webinars in October, focusing on scientific and policy developments in the four disease-specific areas, and the main in-person event in Vienna, comprising governance meetings, plenary sessions, town hall debates, workshops, and a gratitude dinner.

Save the date and join us to drive the change together!

Note: The webinars will be open to the public, while the in-person participation will be by invitation only.

PERFECTO: Now live on Social Media

The PERFECTO Project (Preventing the Preventable – Familial Hypercholesterolaemia Paediatric Screening for Cardiovascular Health) now has a dedicated website and is present on social media (LinkedIn, X, Facebook and Instagram)!

PERFECTO focuses on early detection of inherited high cholesterol in children to prevent severe cardiovascular diseases (CVD). Early identification of familial hypercholesterolaemia (FH) can prevent premature heart attacks and other health issues through healthy lifestyle habits and medication.

The PERFECTO Consortium includes partners from Germany, Romania, Cyprus, and the Netherlands, with support from experts in Ukraine and Bulgaria. The project promotes best practices for FH paediatric screening, focusing on high-burden countries. PERFECTO is co-funded by the European Union under the EU4Health Programme.

Visit our dedicated website and follow us on social media to stay updated!

Facebook Twitter Instagram LinkedIn Website

Project PERFECTO in Cyprus

As part of the **PERFECTO** research project (co-funded by EU4Health), the **Cyprus University of Technology** has just launched an online survey aiming to capture the knowledge, beliefs and attitudes of the population in Cyprus with regards to cardiovascular health and paediatric screening for familial hypercholesterolemia. This will be further complemented by focus group discussions with relevant national stakeholders and will culminate in developing a personalized communications model for Cyprus, informing evidence-based policy and practice in Cyprus and the EU.

Representing the voice of patients and citizens on the Citizen Engagement Board at EP PerMed

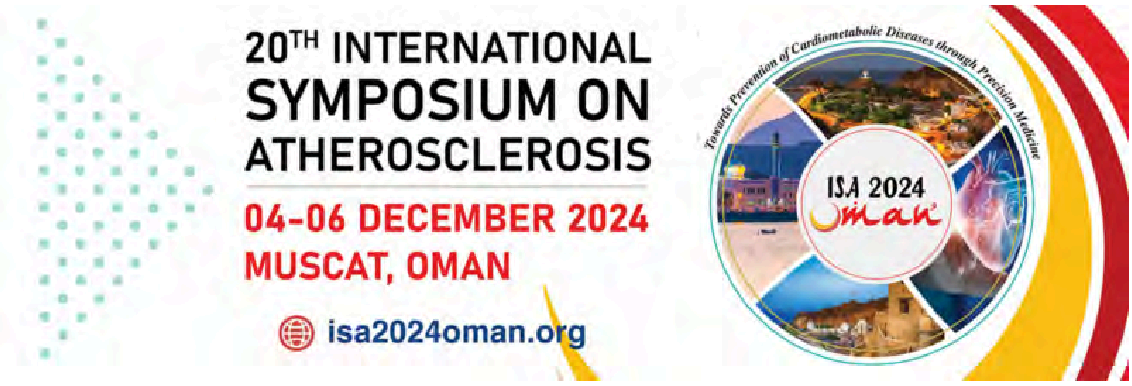
Personalised medicine is a strategic pillar at FH Europe, and we are thrilled to announce that our CEO, Magdalena Daccord, will represent patient and citizen voices on the Citizen Engagement Board (CEB) at EP PerMed, the European Partnership for Personalised Medicine.

Launched in November 2023 and co-funded by the EU, EP PerMed aims to improve health outcomes within sustainable healthcare systems through research, development, and innovation in personalised medicine (PM). The CEB ensures successful citizen engagement and related activities within this partnership.

EP PerMed, as a coordination platform, unites European and international ministries, funding organisations, agencies, and authorities, with over 50 European partners collaborating over the past 10 years. It supports the PM value continuum with actions such as joint research funding, partnerships, tailored tools, and PM implementation activities, all supported by conducive policy and regulatory frameworks.

Magdalena expresses, “It is an incredible opportunity to build on FH Europe’s learnings and collaborate with esteemed CEB experts. I hope to leverage this role to enhance citizen engagement in Precision Medicine, benefiting patients and citizens with inherited lipid disorders across Europe.”

Read more about EP PerMed **here**.



ISA 2024 in Oman: 9 Abstracts Submitted by Our Patient Ambassadors

We are proud to announce that our International Patient Ambassadors have submitted nine abstracts to the 20th International Symposium on Atherosclerosis (ISA 2024) in Muscat, Oman.

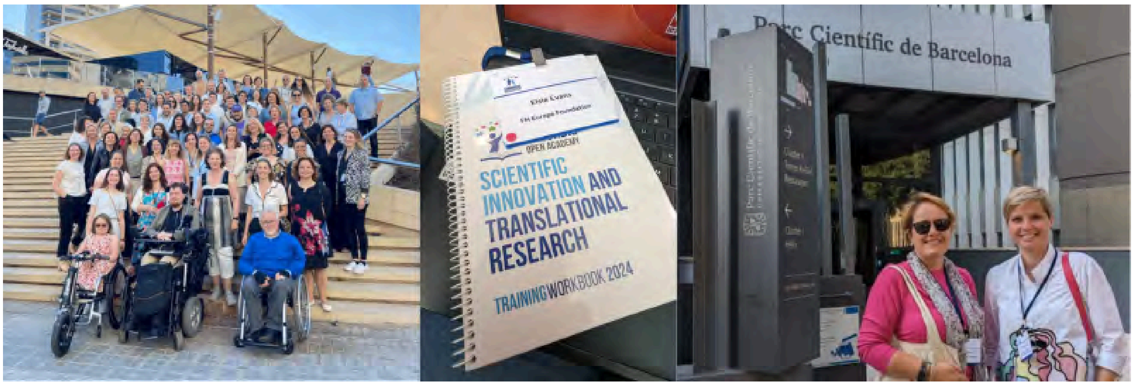
The submissions include:

- 3 abstracts on HoFH: Addressing treatment access, disease burden, health economics, and HoFH Awareness Day.
- 2 abstracts on elevated Lp(a): Highlighting the Lp(a) International Taskforce and patient advocacy driven by lived experiences.

- 2 abstracts on patient organisations in FH: Showcasing examples from the Czech Republic and the Middle East.
- 1 abstract on FCS: Exploring the burden of the disease.
- 1 abstract on the Patient Ambassador Programme: Demonstrating its impact.

Many thanks to Patient Ambassadors Elsie Evans, Jill Prawer, Chyrel Lichaa, Kristýna Čillíková, Marc Rijken, and Tobias Silberzahn for their efforts. Special thanks to Samuel Gidding for his guidance and our industry partners for their support.

Read more about the congress **here**.



FH Europe Foundation at EURORDIS Open Academy 2024: A Transformative Experience for Patient Advocacy

Elsie Evans, FH Europe Foundation's Ambassador Programme Project Manager, attended the EURORDIS Open Academy for Scientific Innovation and Translational Research Training 2024. The event began with EURORDIS CEO Virginie Hivert emphasising patient-centred research and innovation. Notable sessions included Jordan de Graaf's advocacy journey, Nick Meade's insights on Advanced Therapy Medicinal Products, and Dr. Eulàlia Baselga's explanation of natural history studies.

Participants explored genomic analysis at CNAG, with discussions led by Shirlene Badger on secondary findings and Julian Isla on AI in patient empowerment. Annemieke Aartsma-Rus highlighted the importance of incorporating patient perspectives in translational research.

Further sessions covered ethics in genome editing, patient-generated data, and the significance of multi-disciplinary teams. The event concluded with discussions on drug repurposing, featuring impactful presentations by Nick Sireau and Leonardo Panzeri.

This event underscores the vital role of patient advocacy in shaping the future of healthcare.

Read more about EURORDIS’ Open Academy **here**.

Reflections from #ECRD2024: Insights and Inspiration

FH Europe's Ambassador Programme Project Manager, Elsie Evans, represented our community at the European Conference for Rare Diseases and Orphan Products (#ECRD2024) in Brussels. The event brought together diverse stakeholders to discuss best practices and innovative solutions.

A major highlight was our community's accepted abstract on "Quality of Life Living with HoFH" and successful advocacy for an ORPHA code for rare diseases. The "No Health Without Mental Health" session explored a mental health toolkit for rare disease patients, revealing common challenges across conditions. Notable speakers included Kirsten Johnson from EURORDIS and Eva Schoeters from RaDiOrg.

Elsie participated in a breakout session on “compassionate use,” uncovering complexities needing further exploration. The second day featured inspiring talks, including Simona Bellagambi on equitable diagnosis and Sofie Skoubo on using telepresence robots for children with chronic conditions.

Top poster presentations by Gina Cioffi Loud, Sonja Sucic, and Caroline Wernert-Iberg sparked engaging discussions, with one standout being a game designed to educate clinicians about rare diseases. You can take a look at all of the posters **here**.

The conference concluded with a call to action, emphasising the importance of national plans and collective efforts to advance rare disease policies. An **open letter** to European institutions was signed, reaffirming our commitment to these goals. The #ECRD2024 exemplified the power of collaboration and left attendees inspired to drive new initiatives.

Key takeaways for Elsie included the emphasis on community collaboration. The conference highlighted the power of collective action, showing that while individuals may be few, together we form a formidable force. The sense of unity—both in person and online—was palpable throughout the event.

Read more about it **here**.

NETWORK
NEWS

Austria – FHChol

Cooking Class for Families with HoFH

FHChol’s cooking class for families with HoFH was a great success! Four families, whose children regularly undergo apheresis at the AKH Children's Clinic, met for the first time and got to know each other. The introduction took place in a playful manner under the supervision of a psychologist from the AKH Children's Clinic team. We cooked the children's favourite recipes, which were dietetically optimised by Michelle. Everyone participated with enthusiasm! The children have already asked if there will be another meeting like this next year.

Reminder: FCS Online Meeting

As previously announced in our newsletter, FHChol’s upcoming FCS Online Meeting is just around the corner on 9 July. The meeting will feature two insightful presentations, promising to be both informative and engaging. We encourage all to save the date and participate actively in this upcoming session. Don’t miss out on the opportunity to connect and learn more!

Read more about it here.

Preview: FH Symposium on 11 September

Looking ahead, our FH Symposium is set for 11 September. The agenda is packed with insightful lectures and workshops dedicated to familial hypercholesterolemia. Stay tuned for more details soon!

We look forward to your active participation in our upcoming events, aiming to enrich our community's knowledge and support.

Prepared by FHChol Austria

Ireland - Croí

Croí in the Community: Empowering Hearts, Transforming Lives!

Croí, the heart and stroke charity, proudly unveiled its cutting-edge mobile health unit, an initiative made possible by a generous legacy bequeathed to the charity by a local couple. This significant milestone marked a new chapter in Croí's mission to prevent disease, save lives, and promote recovery and wellbeing.

Launched on 23 May 2024, the Croí in Your Community Mobile Health Unit offers advanced facilities and essential health services across Ireland. The event featured interactive demonstrations, health checks, and educational sessions on CPR and cardiovascular risks. Attendees engaged with Croí's Health Team, received personalised health checks, and accessed valuable wellbeing resources.

The mobile unit enhances health accessibility by providing heart health checks, educational resources, and support throughout the region. Croí aims to empower communities to prioritise cardiovascular health and reduce heart disease and stroke risks.

In the coming months, the unit will visit rural and urban areas to offer free cholesterol and blood pressure checks, support, and education to hard-to-reach communities. This transformative project marks a significant step as Croí approaches its 40th year.

Read more about it **here**.

Prepared by Croí

Global Heart Hub

Global Heart Hub partnered with its affiliate, Instituto Lado a Lado pela Vida, Brazil, in convening a national multistakeholder roundtable discussion on integrating patient perspectives into future cardiovascular health policies

On 18 June, Global Heart Hub partnered with its affiliate in Brazil, **Instituto Lado a Lado pela Vida**, to convene a national multistakeholder roundtable discussion on integrating patient perspectives into future cardiovascular health policies. The meeting was organised and hosted by Instituto Lado a Lado pela Vida, which brought together key stakeholders—policymakers, healthcare professionals, and civil society leaders—all of whom are committed to reducing the burden of cardiovascular disease, which is a leading cause of death in Brazil.

Global Heart Hub's Executive Director, Neil Johnson, together with Fernanda de Carvalho, presented findings from the Global Heart Hub **IPEC Study** (Insights from Patients Living with Elevated Cholesterol), a multi-national patient-led research initiative that collected insights on the lived experiences of individuals from Brazil, the USA and Australia who are living with high cholesterol levels.

Read more about it **here**.

Prepared by Global Heart Hub

NEWS
FROM AROUND THE WORLD

European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA)

Help Include Children in Cross-Border Clinical Trials in Europe!

The Working Group of Paediatric Clinical Trials Cross-border Access in Europe, operating under the European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA), has prepared a survey to facilitate the inclusion of children living with diseases in cross-border clinical trials in Europe. Your participation can make a significant impact on this project.

Paediatric Clinical Trials Cross-border Access in Europe can be an opportunity for children living with rare diseases.

If you are a parent, patient advocate, or connected to parents of children living with rare diseases, please take 12 minutes to complete the questionnaire, available in several languages, with more to come!

Complete the questionnaire **here**.

Germany

A new law proposal – the Healthy Heart Act

On June 14th, a draft of the "Gesundes-Herz-Gesetz" (Healthy Heart Act) was proposed by the German Federal Ministry of Health. The new law proposal aims to strengthen cardiovascular health in Germany through a series of measures targeting both early detection and better management of cardiovascular risk factors and diseases.

This comprehensive approach intends not only to reduce the prevalence and impact of cardiovascular diseases but also to manage healthcare costs more effectively by focusing on prevention and early intervention.

Proposed solutions include Early Detection in Children and Adolescents (Mandatory screening for lipid metabolism disorders, particularly familial hypercholesterolemia, for children and adolescents; Legal requirement for health insurance companies to invite children for the J1 examination - a general health check-up during adolescence); Early Detection in Adults (Expanded health check-ups, the "Check-up", at ages 25, 35, and 50 to focus on cardiovascular risks; Health insurance companies must invite insured persons to these check-ups and provide information on how to schedule appointments; Pharmacies will offer advice and risk factor measurements, e.g., diabetes, to encourage participation in check-ups).

Read the original text **here** (in German).

Greece

EPIRUS-FH: Pioneering Reverse Cascade Screening for Familial Hypercholesterolaemia in Greek Youth

Exciting news from Greece! EPIRUS-FH programme has been launched. The registry is a model program of reverse cascade screening for FH in children and adolescents in Northwest Greece that aims to increase public and physician awareness, strengthen the national registry of familial hypercholesterolaemia (HELLAS-FH) and constitute the core for a national FH registry in children and adolescents in Greece.

See further details **here**.
From a post by Fotios Barkas

Japan

In Memoriam: Akira Endo, Father of Statins

On 5 June, 2024, Akira Endo, known as the father of statins, passed away at the age of 90. Endo's pioneering research has been fundamental to the prevention and treatment of cardiovascular diseases. His dedication to science began in his youth in Japan and was greatly influenced by the discoveries of Alexander Fleming.

Endo's career breakthrough occurred after joining Sankyo & Co., where he hypothesised that certain fungi could produce substances to inhibit cholesterol synthesis. This led to the discovery of the first statin, compactin, fundamentally changing heart disease treatment. Despite early setbacks, his perseverance paved the way for the development of safer statins, revolutionising cardiovascular healthcare.

Endo's legacy lives on through his monumental contributions to medicine and the countless lives saved by his work. His awards, including the prestigious Albert Lasker Award, underscore the global impact of his scientific endeavours.

Read more about Akira Endo and his legacy **here**.

PARTNER NEWS

EAS - FHCS

Enhancing Identification of Familial Hypercholesterolemia in Electronic Health Records with AI

Researchers from the coordinating centre of the European Atherosclerosis Society Familial Hypercholesterolaemia Studies Collaboration (EAS FHSC) have published a new article showing that AI could help identify individuals carrying a genetic variant linked to familial hypercholesterolaemia (FH). Their article, published in the Journal of the American Heart Association (JAHA), demonstrates that AI models can identify “true” (i.e., genetically defined) FH in electronic health records with greater sensitivity and precision than existing methods and the screening criteria recommended in the UK. Their model could thus enhance the identification of “true” FH, which is currently diagnosed in less than 10% of cases globally, potentially leading to an improvement in the management of FH individuals and helping to reduce the high number of cardiovascular events caused by this condition.

The predictive study included 454,710 participants from the UK Biobank, 1,003 of whom were found to have a pathogenic FH-causing variant in the LDLR, APOB, or PCSK9 genes. The best AI model derived in the study outperformed existing clinical criteria and the recommended screening criteria, reducing the number of necessary tests by about one-third to identify more carriers of FH variants compared to current methods. The researchers are now planning to validate their model in different populations before implementing it in a clinical setting. Implemented in electronic health records, this tool could offer a scalable and potentially cost-effective solution to identify individuals most likely to benefit from a confirmatory genetic test for FH.

Read more about it **here**.

Update on the EAS Familial Hypercholesterolemia Studies Collaboration (FHSC)

The FHSC Genetics Project data collection stage has been completed as of May 2024. The FHSC is now the largest database to date of the spectrum of DNA mutations and protein variants causing FH, as well as non-FH-causing variants discovered upon genetic testing for suspected FH.

The FHSC Genetics Project includes >40,000 patients with FH from >40 countries across all world regions. The project aims to map the most common FH variants detected in various world regions and to provide practical recommendations for best practices in FH genetics testing. The project will also enhance our understanding of how genotype and environment, including geographical location, interact to determine disease severity and outcomes in patients with FH.

Interim findings from two of the project studies were presented at the 2024 EAS Congress in Lyon by FHSC Researchers Amany Elshorbagy and Christophe Stevens.

- **Presentation 1**: Spectrum of gene variants in children and adults with heterozygous familial hypercholesterolaemia (fh) across world regions: a study by the EAS-FH studies collaboration (FHSC)

- **Presentation 2**: To correct or not to correct (for treatment): estimating pre-treatment LDL-C concentrations in genetically characterised patients with familial hypercholesterolaemia on lipid-lowering medication

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EURORDIS

EU4Health Must Recognise Added Value of EU Action on Rare Diseases

Following the EU4Health Stakeholders' Conference, EURORDIS urges the European Commission to prioritise rare disease needs in the EU4Health 2025 Work Programme. Despite budget cuts, EURORDIS welcomes the Commission's efforts and stresses the significant added value of EU action on rare diseases.

EURORDIS calls for a European Action Plan for Rare Diseases, standardised newborn screening, support for European Reference Networks, and a Single Market for rare disease therapies. They also recommend adopting digital health technologies and a Mental Health Toolkit.

The rare disease community strongly supports these priorities and looks forward to collaborating with the new Parliament on inclusive health policies that benefit 30 million Europeans with rare diseases.

Read more about it **here**.

European Parliament Elections 2024: What They Mean for Rare Disease Advocacy

The recent European Parliament elections will significantly impact the rare disease community across Europe. The newly elected MEPs will set legislative and budgetary priorities, elect key officials, and approve the new President and College of Commissioners, who will address rare diseases.

Despite a €1 billion health budget cut, 90 candidates signed the #ActRare2024 campaign pledge to support 30 million Europeans with rare diseases. Key health policy areas include the European Health Union, the Pharmaceutical Strategy for Europe, and the European Health Data Space.

A European Action Plan for Rare Diseases is highly anticipated. EURORDIS remains committed to advocating for rare diseases and will work closely with the new Parliament and Commission to prioritise these policies.

Read more about it **here**.

European Patients Forum

European Patients' Forum Calls on New MEPs to Prioritise Health in the EU Agenda

The European Patients' Forum (EPF) welcomes the newly elected Members of the European Parliament (MEPs) following the recent EU elections. The EPF urges these representatives to prioritise health on the EU agenda.

Introducing the Patient Organisations’ Manifesto, EPF outlines a vision for the next decade, emphasising the importance of patient organisations in shaping healthcare policies. The #Vote4Patients campaign highlights the critical impact of MEPs' decisions on European healthcare, calling for patient involvement in policy debates.

The Manifesto advocates for the meaningful involvement of patient organisations in policy development and healthcare processes. EPF President Marco Greco emphasises that current health policies will define the future of millions of Europeans. EPF will collaborate with MEPs to ensure equitable healthcare access and impactful policy changes, guided by the Manifesto's principles for better health in Europe.

Read more about it **here**.

LEEFH

Novel Strategies to Improve Detection and Treatment

Shirin Ibrahim, who has made significant contributions to public understanding of FH via the **FH Explainer video** that simplifies and uniquely presents information about FH, recently successfully defended her PhD thesis, "Familial Hypercholesterolemia: Novel Strategies to Improve Detection and Treatment," at the Oude Lutherse Kerk.

Her groundbreaking research focuses on using central laboratory algorithms and electronic health records to identify familial hypercholesterolemia early, laying a solid foundation for future advancements.

Read her research **here**.

Novel Strategies to Improve Detection and Treatment

The final figures of the cascade screening in 2023 in the Netherlands are known. The LEEFH network, now comprising 36 centres (hospitals), continues to make strides in improving cascade screening and testing more family members.

The results prove that cascade screening is an efficient way to detect familial hypercholesterolemia (FH) early. Impressively, 50% of the detected family members are 18 years of age or younger. In 2023, the Netherlands saw the highest number of FH+ detections in a decade, with a total of 851 cases identified. This highlights the crucial role of cascade screening in early detection and the importance of ongoing efforts to enhance these programmes.

World Heart Federation - WHF

Advocating for Heart Health at WHA77

The World Heart Federation (WHF) represented the global cardiovascular community at the 77th World Health Assembly, which concluded on June 1, 2024.

WHF called for enhanced circulatory health services, prioritised primary care, effective UHC interventions, action on fossil fuel health impacts, and a Global Plan on Climate Change and Health. They also highlighted cardiovascular disease in women and rheumatic heart disease and supported global health and pandemic agreements.

The Assembly adopted key resolutions on health, including climate change. WHF hosted events on critical cardiovascular issues like cardiometabolic and rheumatic heart diseases.

WHF continues to prioritise cardiovascular health in collaboration with WHO and Member States, leading up to the 2025 UN High-Level Meeting on NCDs.

Read more about it **here**.

World Heart Summit: A Gathering for Global Cardiovascular Health

The 9th edition of the World Heart Summit took place in Geneva, Switzerland, from 24-26 May 2024, ahead of the 77th World Health Assembly. Leaders from government, business, civil society, and academia convened to address pressing global challenges in cardiovascular health.

The summit began with an opening plenary discussing the nexus between cardiovascular health and environmental change. A ministerial panel focused on universal health coverage and health financing for cardiovascular disease (CVD). Various panel discussions explored diverse health system approaches, social determinants of health, and the impact of AI on cardiovascular health. Special sessions addressed the dual burden of CVD and mental health, the implementation of the HEARTS Technical Package, and women's cardiovascular health.

The World Heart Federation emphasised the urgent need for global action on CVD and now provides free recordings of all sessions, ensuring wide accessibility.

Read more about it and watch the recordings **here**.

NEW
PUBLICATIONS

Eight Reasons Why Lipoprotein(a) Should Be Measured At Least Once in a Lifetime

In the article "Eight reasons why Lipoprotein(a) should be measured in everyone at least once in a lifetime" by Benoit J. Arsenault and Pia R. Kamstrup, published in the European Heart Journal, the authors highlight the critical importance of measuring

Lipoprotein(a) [Lp(a)] for cardiovascular health. Lp(a) is a highly atherogenic lipoprotein found in high concentrations in individuals with certain genetic variants, affecting about 20% of the population.

Key reasons for measuring Lp(a) include identifying individuals at high genetic risk of cardiovascular disease (CVD), improving management of conventional risk factors, and aiding in the early diagnosis of CVD in those with few traditional risk factors. Measuring Lp(a) can also prevent cardiovascular events in high-risk families and is a low-cost method compared to other invasive risk assessment tools.

Despite its importance, Lp(a) is infrequently measured, often due to a lack of awareness among healthcare professionals. Routine Lp(a) screening can empower both patients and providers to take proactive steps in cardiovascular disease prevention and management.

Read more about it here.

TREATMENT NEWS

Promising news for people living with FCS

On 3 June, Arrowhead Pharmaceuticals, Inc. announced topline results from the pivotal Phase 3 PALISADE study of investigational plozasiran in patients with genetically confirmed or clinically diagnosed familial chylomicronemia syndrome (FCS), a severe genetic disease with significant unmet need and no FDA approved therapies. PALISADE successfully met the primary endpoint of lowering triglycerides and met all key secondary endpoints, including reducing the incidence of acute pancreatitis compared to placebo.

Read more about it here.

SAVE THE DATE

- **30 August - 2 September** - European Society of Cardiology Congress 2024
- **9 - 12 September -** 47th edition of the European Lipoprotein Club
- **17 September** - World Patient Safety Day and World Apheresis Day
- **24 September** - FH Awareness Day
- **29 September** - World Heart Day
- **1 November** - FCS Awareness Day
- **8 - 10 November** - FHEF Annual Network Meeting 2024

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