
Welcome to FH Europe Foundation's January 2025 edition of Heart Beat.



FH Europe Foundation
The European Familial Hyperlipidaemias Foundation

Heart Beat News

FH Europe Foundation Januar 2025 Heart Beat Newsletter

Welcome to the January FH Europe Newsletter! As the first month of the year unfolds, it offers a valuable moment to reflect on the past and envision what lies ahead. We are thrilled to share some exciting news and updates that mark the beginning of 2025 with energy and purpose.

We are proud to have signed the coalition for the WHA Resolution and Global Health, further strengthening our commitment to impactful advocacy. With great joy, we officially welcome the Croatian Dyslipidaemias Organization as the newest member of our network, a testament to our growing community. January also brings a spotlight on our patient ambassadors and Community Engagement Manager, who will represent FH Europe at the prestigious EURORDIS Black Pearl Awards.

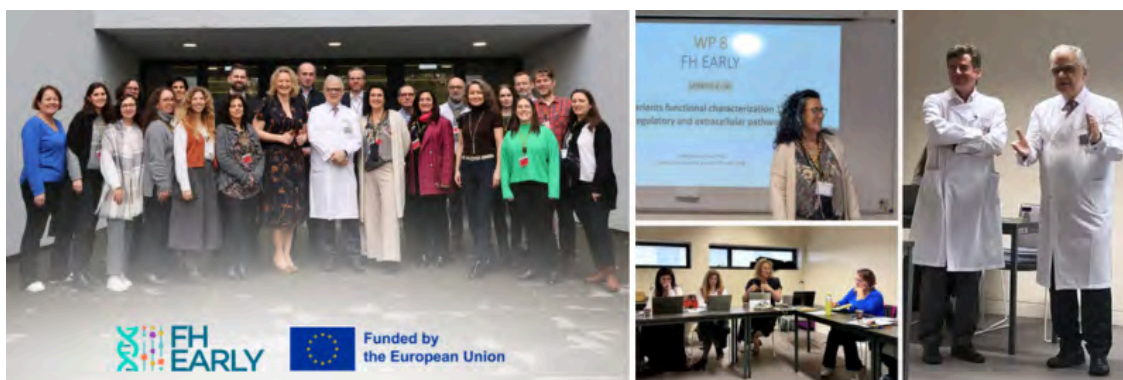
Looking forward, we're delighted to announce the launch of the FH Early project, an initiative of immense importance, alongside the inaugural Lp(a) Summit, which will take place in Brussels. This edition also features news from our network members in Hungary, Heart UK, and Global Heart Hub, as well as updates from key partners including EURORDIS, the European Patients Forum, EAS FHSC, and the EAS Congress.

To top it off, don't miss an insightful new study showcasing 44 years of FH trends in Denmark.

We hope you enjoy this edition and wish you a fantastic weekend ahead!



FH EUROPE FOUNDATION NEWS



FH-EARLY: Revolutionising FH Diagnosis and Co-Management

The ambitious FH-EARLY project officially launched on January 1, 2025, with a €7.25M grant under Horizon Europe, aiming to transform care for familial hypercholesterolaemia (FH). Spanning four years, the project unites 15 partners from Europe, Lebanon, and Turkey to address underdiagnosis, care gaps, and the psychosocial barriers affecting millions worldwide.

Led by AIDFM in Portugal, [FH-EARLY](#) combines cutting-edge genomics, AI, and patient advocacy. Key innovations include a Next-Gen Chip Array for faster genetic testing, a biomarker-based risk stratification tool, and an explainable AI-driven precision health platform. The project prioritizes patient voices, engaging families—including youth aged 16-24—to co-create solutions that are practical, equitable, and culturally sensitive.

FH-EARLY brings hope for earlier diagnosis, better care, and fewer cardiovascular events, paving the way for a brighter future for FH patients globally.

Read more about it [here](#).



Lp(a) Global Summit

We are excited to announce the **first-ever Global Summit on Lp(a)**, which will take place in **Brussels on March 24-25, 2025**, coinciding with Lp(a) Awareness Day. This milestone event will culminate in the Brussels Declaration on Lp(a), which will feed into and shape the policy discourse on the importance of elevated Lp(a) measuring at the European and International levels.

Echoing the increasing political support for a [European Cardiovascular Health Plan](#), and an International Code on CVH, the Summit will be a powerful illustration of why collaboration in the Cardiovascular Health space is vital, with the need to engage many different stakeholders, including, crucially, people with lived experience of the condition.

The invitation-only event is a critical milestone in the work of the [International Task Force on Lp\(a\)](#), convened by FH Europe Foundation and chaired by Prof. Florian Kronenberg, and will mark the launch of the Lp(a) Global Assembly, ensuring that all the key players in this space unite to pursue the vision that everyone is tested once in a lifetime as early as possible in the life course. The Summit will present for the first time an international cost-effectiveness study that demonstrates unequivocally that testing for Lp(a) makes financial sense for health systems, in addition to the vital human and societal benefits of preventing CVD and managing associated risk factors.

For more information, please contact the FHEF Secretariat.



WHA Resolution

A Milestone for Rare Diseases: The WHA Resolution and Global Health

Rare diseases affect over 300 million people worldwide, highlighting the need for equity and inclusion in global health. The upcoming WHA resolution on rare diseases marks a pivotal step in addressing their needs through a Global Action Plan under universal health coverage (UHC).

Led by Egypt and Spain, with co-sponsors from Qatar, Malaysia, France, and Panama, the resolution calls for improved diagnosis, care access, and stigma reduction. Building on the 2021 UN resolution, this initiative transitions from principles to actionable outcomes.

We at FH Europe Foundation fully support this groundbreaking resolution, standing with the rare disease community to drive awareness and action. As February 28 approaches, the momentum grows to ensure this resolution's adoption in May 2025—a milestone for millions.

Read more about it [here](#).



FH Europe Ambassadors at the EURORDIS Black Pearl Awards

We are delighted to share that our Patient Ambassadors will be attending the esteemed EURORDIS Black Pearl Awards on February 24, 2025, in Brussels. This prestigious annual event, held in conjunction with Rare Disease Day,

celebrates outstanding individuals and contributions within the rare disease community.

Representing the familial hyperlipidaemias community are Helga Davidson from Scotland and Athanasios Pallidis from Greece. Helga's dedication to raising awareness and providing education for the FCS community has made a significant impact, while Thanos, a 2021 EURORDIS Young Advocate Award finalist, has tirelessly worked to advance HoFH awareness, advocacy, and policy. This year marks a special opportunity for Thanos to experience the event in person after COVID restrictions in 2021 prevented him from attending.

Accompanying the ambassadors is Emma Print, FH Europe's Community Engagement Manager, who looks forward to connecting with peers from the international rare disease community and bringing valuable insights back to FH Europe.

Stay tuned for updates from the EURORDIS Black Pearl Awards and join us in celebrating Rare Disease Day by registering for our webinar **More Than You Can Imagine – Rare Disease Day** through the Lens of HoFH and FCS and participating in our Rare Disease Day campaign.

Register for the webinar [here](#).

Read more about it [here](#).



Welcoming Croatian Dyslipidaemia Patients Association as New Network Member

FH Europe Foundation proudly welcomes the Croatian Dyslipidaemia Patients Association to our network of patient organisations! Founded in December 2023 by HeFH patient and president Iva Prgomet, with support from Prof. Ivan Pećin, the association is dedicated to raising awareness about familial hyperlipidaemias and cardiovascular health.

Their innovative campaigns, like the Zagreb Advent Run and public cholesterol

testing, address Croatia's low 5% detection rate of dyslipidaemia. Public outreach through transport ads and billboards further amplifies their message.

We're thrilled to co-host the 2025 Annual Network Meeting in Zagreb, fostering collaboration and progress. Together, we aim to improve patient outcomes and fight cardiovascular diseases across Europe. Welcome aboard!

Read more about it [here](#).



Breakthrough in Understanding LDL Structure

Gilles C. Lambert and **Simon G. Pfisterer** have made a major discovery about the structure of **apolipoprotein B100 on LDL** (Apolipoprotein B100 is a protein on LDL (cholesterol) that helps carry cholesterol through your blood). Using **advanced cryo-electron microscopy and AI** (Cryo-EM lets us see tiny biological structures in great detail, and AI helps us make sense of the complex data produced by this technique), they have detailed how LDL interacts with its receptor. This is a big step forward in understanding **familial hypercholesterolaemia (FH)** and developing new treatments.

Key Points:

- **LDL particles** carry cholesterol in the blood.
- High LDL levels can cause **heart attacks and strokes**.
- The new research shows a **β-belt** structure around LDL particles.
- This helps in creating better **cholesterol-lowering drugs**.
- It also helps in understanding **familial hypercholesterolaemia (FH)**, a genetic disorder that causes high cholesterol levels.
- By targeting specific parts of apoB100, new drugs can be developed to improve **LDL clearance** from the blood, managing levels better and reducing the risk of cardiovascular diseases.

This discovery is important for the **FH Europe community** because it helps us understand FH better and find new ways to treat it.

FH Europe Foundation is proud to be part of the [PerMed FH project](#), sharing these important findings. For more information, visit the [Nature Reviews Cardiology for the full article](#).

Hungary - SZÍVSN

SZÍVSN Campaign for Ópályi Concludes

SZÍVSN successfully completed the “We Help the People of Ópályi!” campaign in December 2024, with government support. The initiative aimed to improve cardiovascular health in Northern Hungary’s impoverished regions, screening 241 residents.

Key health checks included blood glucose, cholesterol, weight, blood pressure, and ECGs. Results revealed high rates of hypertension, high sugar, elevated cholesterol levels, and arrhythmias among both women and men.

The campaign also featured CPR training and a lecture on contraception by the Budapest Medical Students Association. With donated equipment, SZÍVSN has laid the groundwork for long-term health improvements in the region.

Read more about it [here](#).



UK – Heart UK

HEART UK Launches New Diet and Lifestyle Plan: Cholesterol Smart

HEART UK is proud to introduce Cholesterol Smart, a comprehensive diet and lifestyle plan created by their nutrition experts. Designed to make cholesterol-lowering practical and achievable, the plan provides tips, tools, and recipes to help individuals take control of their heart health.

Cholesterol Smart offers a flexible, step-by-step approach that fits any lifestyle, enabling users to progress at their own pace. From small adjustments to significant changes, each step leads toward healthier blood cholesterol and improved heart health.

The plan features five actionable steps: setting a positive mindset, evaluating current habits, creating personalised goals, implementing practical changes, and celebrating progress. It also includes cholesterol-smart recipes, offering options for various dietary needs, including vegan and budget-friendly meals.

HEART UK's Cholesterol Smart empowers individuals with the confidence and tools to achieve lasting results for better heart health.

Read more about it [here](#).

The Netherlands - VrouwenHart

VrouwenHart Reflects on a Successful 2024

The VrouwenHart Foundation celebrates a fruitful 2024, marking its fourth year of advocating for women's heart health. With over 20,000 followers, including patients, cardiologists, and researchers, the foundation has strengthened awareness of how female hearts differ from male hearts.

Key achievements include publishing *Women Also Get a Heart Attack*, contributing to groundbreaking research, and hosting impactful events like the Nieuwspoord meeting in The Hague. VrouwenHart also fostered peer connections through Facebook groups and live events.

Looking ahead, 2025 promises a revamped website, anniversary celebrations, and more campaigns to amplify their mission.

Read more about it [here](#).



Global Heart Hub

READI Project Launch: Advancing Inclusivity in European Clinical Research

On January 16, 2025, the READI project (Research in Europe and Diversity Inclusion) officially launched. This six-year initiative, funded by Horizon Europe, aims to enhance the inclusion of underserved populations in clinical studies across Europe by fostering a more inclusive and cohesive research ecosystem.

As a key partner, Global Heart Hub plays a vital role in promoting the representation of under-represented groups in cardiovascular research. Their efforts focus on addressing unique challenges, mapping stakeholder networks, and fostering connections between patients, researchers, and healthcare providers. By building trust and encouraging collaboration, they contribute to advancing health equity and improving outcomes for diverse patient populations.

READI represents a significant step forward in creating a patient-centred and inclusive clinical research landscape.

Read more about it [here](#).



NEWS
FROM AROUND THE WORLD

RARE DISEASES INTERNATIONAL

PUBLIC WEBINAR
12 February 2025
14:00-15:00 CET

RARE DISEASE EXPERTISE, CENTERS and NETWORKS:
RESULTS OF THE PUBLIC SURVEY

Rare Diseases International

Public Webinar: Rare Disease Expertise, Centers, and Networks – Results of the Survey

Rare Diseases International (RDI) is inviting you to a public webinar to share the findings of its recent survey on centres and networks providing care for rare diseases around the world.

The webinar will take place on Wednesday, 12 February, at 14:00 CET. It will highlight key insights into rare disease expertise, focusing on care-providing

centers, networks, and global collaborations.

Read more about it [here](#).



World Patient Alliance

Public Webinar on Precision Medicine

The World Patients Alliance recently hosted a webinar featuring Marius Geanta, a former FH Europe Foundation trustee and advisor, who explored the transformative potential of precision medicine. This innovative approach tailors treatments to individual patients, revolutionising healthcare.

What is Precision Medicine?

Precision medicine considers genetic, environmental, and lifestyle factors to deliver personalised care, moving beyond one-size-fits-all treatments. It is especially critical for inherited lipid conditions like familial hyperlipidaemia (FH), where early detection and targeted therapies can greatly improve health outcomes and quality of life.

European Projects and FH Europe Foundation's Role

FH Europe Foundation is actively involved in projects such as [PerMedFH](#), [PERFECTO](#), and [FH-EARLY](#), which focus on advancing precision medicine in inherited lipid conditions. These initiatives align with the mission of “preventing the preventable” through early diagnosis and personalised treatments.

The webinar emphasised precision medicine’s potential to reshape healthcare. You can watch the recording of the webinar [here](#).

For our German-speaking friends! Lp(a) – a common risk factor for heart attack & Co.

Heart attacks and strokes can often come suddenly and surprisingly for those affected and their relatives. But in the meantime, we know very well about important risk factors. In addition to high cholesterol levels, an elevated Lp(a)

value is one of the most important genetic risk factors for these diseases. This "blood fat" is significantly increased in every fifth person and occurs in families.

In his presentation, Florian Kronenberg, director of the Institute of Genetic Epidemiology, and Chair of the [Lp\(a\) International Task Force](#), explained what this Lp(a) is and why there are families in which several people are affected by elevated Lp(a) values and heart attacks, strokes, arterial occlusive diseases and aortic valve calcifications occur more frequently than expected. In addition, the questions of how we can counteract this risk and what possible therapies of the future look like were answered.

You can access it [here](#).

Please note that this presentation is in German.



**PARTNER
NEWS**

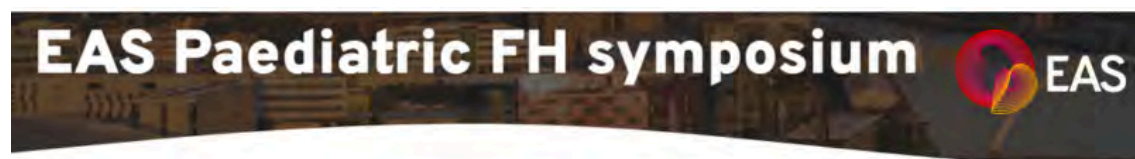
EAS FH Studies Collaboration (FHSC)

Obesity in Patients with Familial Hypercholesterolaemia Globally

The EAS FHSC Investigators at Imperial College London have published a pivotal study in the European Heart Journal. Titled Overweight, obesity, and cardiovascular disease in heterozygous familial hypercholesterolaemia, the study draws on data from over 35,000 individuals globally.

Findings reveal that obesity is prevalent in patients with HeFH and is linked to more severe hyperlipidaemia and an elevated risk of cardiovascular disease from childhood. The research underscores the importance of early diagnosis, including childhood screening, and emphasizes a holistic approach combining healthy weight management and LDL-C-lowering treatments to improve long-term outcomes.

Read more about it [here](#).



Welcome to the 8th EAS Paediatric Familial Hypercholesterolemia Symposium

Saturday, 3 May 2025, Glasgow, UK

**SAVE
THE DATE**

EAS

8th EAS Paediatric FH Symposium – Save the Date

The 8th EAS Paediatric Familial Hypercholesterolaemia Symposium will take place on Saturday, May 3, 2025, at the Crowne Plaza Glasgow in the UK. This event is a key gathering for experts, advocates, and healthcare professionals dedicated to advancing care for children with FH.

The program will cover vital topics, including the clinical utility of understanding the genetic causes of FH in children, updates to the EAS Paediatric FH Guidelines for 2025, and discussions on innovative treatments such as PCSK9 and ANGPTL3 inhibitors. Organised by renowned specialists, the symposium offers an exceptional platform for knowledge-sharing, collaboration, and networking.

Registration is free and will open soon. Don't miss this opportunity to connect with leading voices in the field and contribute to improving paediatric FH care.

Read more about it [here](#).

EAS Young Investigator Awards for Outstanding Publications

The European Atherosclerosis Society (EAS) is accepting nominations for the annual Young Investigator Awards, recognizing exceptional publications in the fields of atherosclerosis and related metabolic disturbances. Two awards, one for basic science and one for clinical research, each carry a prize of €2000.

Eligible articles must be authored by individuals 40 years or younger and published in English between January 1 and December 31. Nominations, including self-nominations, must be submitted to EAS by individuals or Student members using the official nomination form.

The deadline for submissions is January 31, 2025. Award recipients will be announced in March, with the ceremony held during the EAS Congress Opening Ceremony.

Read more about it [here](#).

European Patients' Forum

EPF's Policy Priorities for the New EU Mandate

As the European Health Union faces growing cross-border health challenges, the European Patients' Forum (EPF) has outlined patient-centred proposals to enhance equitable access to healthcare, address medical product shortages, and strengthen healthcare systems.

Key priorities include:

- **Equitable Access to Healthcare:** Tackling inequalities, expanding regional cooperation on medicine pricing, and ensuring effective implementation of the Health Technology Assessment Regulation.
- **Medical Product Shortages:** Establishing solidarity mechanisms, promoting resilient supply chains, and assessing medical device regulations.
- **Cross-Border Health Threats:** Combatting antimicrobial resistance and ensuring sustainable healthcare systems during the green transition.
- **EU Health Funding:** Strengthening EU4Health funding and prioritizing digital health literacy initiatives like Data Saves Lives.

Read the full report for EPF's actionable proposals to make healthcare systems more inclusive and patient-focused [here](#).

Skills Training for Young Patient Advocates (STYPA), focusing on Digital Health and AI

EPF is thrilled to launch the 2025 edition of ShapeSkills Training for Young Patient Advocates (STYPA), focusing on Digital Health & AI. This unique program equips young patient advocates with essential knowledge on digital health, AI, data governance, and ethical challenges, empowering them to advocate for patient-centered innovation.

Why join STYPA 2025?

- Gain insights into digital health and AI's impact on patient care.
- Understand ethical concerns like privacy, equity, and transparency.
- Learn practical advocacy skills to influence healthcare policies.
- Connect with a network of young patient leaders shaping the future of healthcare.

Who Can apply?

Young advocates (age 18-30) from European countries with a passion for patient rights, digital health, and AI. Applicants should have a strong command

of English (C1) and be engaged in patient advocacy.

Key Dates

- Intro Webinar – June 2025
- In-person Training – July, 3-6 2025, Brussels, Belgium (travel & accommodation covered)
- Follow-up Webinars – August-October 2025

You can apply by completing this application form. If you have any additional questions or issues with your application, please contact the EPF Staff at stypa@eu-patient.eu for questions. The deadline for application is March 16, 2025.

You can register for the webinar [here](#).

World Heart Federation

Davos Declaration Targets Urban Heart Health

On January 21, 2025, the World Heart Federation (WHF) and the Novartis Foundation unveiled the Davos Declaration on Urban Heart Health at the World Economic Forum, urging global leaders to address cardiovascular disease (CVD), the leading cause of death and disability worldwide.

As urban populations grow to 70% by 2050, cities play a pivotal role in combating CVD. The Declaration outlines a strategy to improve care quality, accelerate disease detection, and leverage data and technology to enhance heart health. Key commitments include ambitious health targets, regular progress monitoring, and multi-sectoral policy reforms.

WHF President Dr Jagat Narula emphasized urban centers as critical battlegrounds for CVD prevention, while Dr Ann Aerts of the Novartis Foundation highlighted the transformative power of precision tools and real-time data in advancing population health.

The initiative builds on the CARDIO4Cities model and promotes a global network of cities committed to reducing CVD through innovation and collaboration.

Read more about it [here](#).

Breaking news!

Season of Hope: Transformative Milestones in Rare Lipid Disorders

At the beginning of the new year, the rare lipid disorder community received incredible news of two groundbreaking developments offering hope for families affected by Homozygous Familial Hypercholesterolaemia (HoFH) and Familial Chylomicronaemia Syndrome (FCS).

First-Ever Treatment for HoFH in Children as Young as 6 Months

The European Commission has approved evinacumab for children as young as 6 months old with HoFH, marking a historic step forward. This is the first treatment in Europe for children under 5 suffering from this life-threatening genetic condition, which causes dangerously high cholesterol levels and early cardiovascular complications.

This approval provides a new pathway to reduce LDL cholesterol levels early in life, potentially altering the disease's progression and improving quality of life for children and their families. For parents, this is a beacon of hope and a step toward a brighter future.

Read more about it [here](#).

A Breakthrough for FCS Patients in the USA

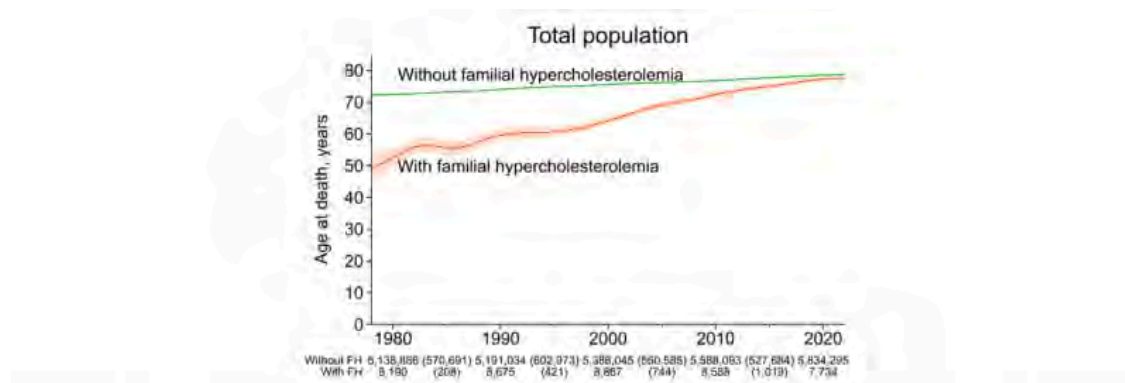
In a similarly groundbreaking development, the FDA has approved olezarsen, the first treatment for adults with FCS in the United States. FCS is a rare genetic disorder that leads to extremely high triglyceride levels, causing acute pancreatitis and chronic symptoms that significantly impact daily life.

This new therapy, delivered monthly via an auto-injector, not only reduces triglyceride levels but also lowers the risk of acute pancreatitis—offering a life-changing opportunity for patients and their caregivers.

These advancements underscore the importance of early diagnosis and intervention, as well as the continued push for innovative therapies to address the needs of those with rare lipid disorders. They also serve as a reminder of the progress being made in the fight against these conditions, bringing hope and relief to families who have waited so long for effective treatment options.

Read more about it [here](#).





New Study Highlights 44 Years of FH Trends in Denmark

The European Heart Journal recently published a groundbreaking study: Ages at coronary heart disease and death in familial hypercholesterolaemia: a Danish nationwide study spanning 44 years by Jacob Reeh, Shoaib Afzal, Anders Berg Wulff, and Børge G. Nordestgaard.

Denmark, the only country systematically recording familial hypercholesterolaemia (FH) diagnoses since 1978, offers unique insights into long-term trends in FH outcomes. This retrospective cohort study analyzed data from over 10,000 individuals with FH and nearly 9.2 million without FH between 1978 and 2021.

Key findings include:

- Age at death: Normalised over time, becoming comparable to individuals without FH by 2021.
- Age at coronary heart disease: Improved but remains significantly younger—7 years earlier for those with FH in 2021 compared to those without FH.

These results highlight the importance of early diagnosis and treatment in improving life expectancy while underscoring the ongoing risks of coronary heart disease in FH patients.

Access the full article for detailed findings [here](#).



Did you know that traditional Chinese New Year dishes like dumplings, longevity noodles, and Lion's Head Meatballs symbolize prosperity, longevity, and family unity? Helga Davidson has adapted these festive recipes to be suitable for individuals living with familial chylomicronemia syndrome (FCS) and homozygous familial hypercholesterolemia (HoFH), ensuring they meet dietary

needs without compromise.

[Click here to explore the recipe](#) and give it a try. Happy cooking!

Note: When accessing these recipes, please remember to consult the content carefully, especially if you have a diagnosis of FCS or medication restrictions.

**SAVE
THE DATE**

- **February 14** - Europe Rare Disease Summit
 - **February 28** – Rare Disease Day
 - **March 24** – Lp(a) Awareness Day
 - **March 24-25** – Lp(a) Global Summit, Belgium
 - **May 4** – HoFH Awareness Day
 - **May 17-18** – World Heart Summit, Switzerland
 - **November 14-16** – FH Europe Foundation Annual Meeting, Croatia
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