



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

**Heart Beat News**

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

Welcome to our Spring Heart Beat News!

This spring, we proudly celebrated the first HoFH Awareness Day on May 4th with the slogan One Galaxy, One Heart: Unite for HoFH Awareness. This initiative is a significant step in raising awareness and advocating for people with rare and severe familial hypercholesterolaemia (FH), so check out how you can get involved.

Throughout the season, our team, as well as our patient ambassadors have participated in numerous meetings and events, where we have learned, shared experiences, raised awareness and represented the needs of people living with familial hyperlipidaemias HeFH, HoFH, elevated Lp(a) and FCS. At the 92nd EAS Congress in Lyon, our first-ever booth was busy with engagements and

building connections between patients and medical professionals, initiating collaborations with potential partners and many more. Patient and cardiovascular health, prevention and innovation were very much at the forefront during the congress, with Ambassadors speaking in 5 different sessions, PERFECTO, PerMed FH and Lp(a) International Taskforce projects presented.

We are excited to share important updates from our network members! Austria hosted dynamic events, Croatia launched a major public health campaign on cardiovascular disease awareness, and an Estonian family shared their experience of living with FCS. We also have news from Hungary, Ireland, Italy, Poland, Latvia, and the UK.

In this edition, read inspiring stories about living with HoFH and caring for a little patient with FCS. Find updates from our partners, including EURORDIS's new guide on the Patient Journey, findings on newborn screenings, and the European Patients Forum's advocacy efforts. Also, look out for the World Heart Federation's upcoming event before World Heart Day.

Enjoy reading and have a lovely weekend ahead!



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**FH EUROPE FOUNDATION**  
**NEWS**



## The first-ever HoFH Awareness Day campaign has been launched!

We are thrilled that the first-ever HoFH Awareness Day campaign with the slogan: One Galaxy, One Heart: Unite for HoFH Awareness has been launched and shared with the global community, and you can read all about it on the dedicated [HoFH Awareness Day website](#).

Thank you to everyone who got involved and has been a part of this incredible campaign - from our incredible Rebel Partners to each patient, patient ambassador, caregiver, healthcare professional, researcher and other individual - your participation matters, and your voice is being heard and together we can make HoFH Awareness Day a global success.

We also extend our sincerest gratitude to our industry partners [Arrowhead Pharmaceuticals](#), [Chiesi Group](#), [Regeneron](#), [Ultragenyx](#), whose unwavering support has fueled our mission.

Together, we are a force to be reckoned with, and your partnership empowers us to make a meaningful difference every day. Let's [#Unite4HoFH](#) on May 4th and beyond.

The greater HoFH Awareness Campaign will last till September 24, FH Awareness Day. So, watch out for more valuable information and inspiring stories from individuals supporting HoFH Awareness Day. Engage with us on social media by liking, sharing, and commenting on our posts. You can also participate in our Logo Competition or take the HoFH Survey. For those interested in active collaboration, please reach out to [Chyrel Lichaa](#).

Read more about it [here](#).



### HoFH 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 chance to be part of something special. [Visit the Logo Competition Website](#) to learn how you can save lives and unite a global community of individuals and their relatives living with a rare disease.

# The Impact of HoFH

## SURVEY

NOW AVAILABLE IN MULTIPLE LANGUAGES!



SCAN ME

### HoFH Quality of Life Survey now Available in Multiple Languages!

We are pleased to share that the survey aiming to capture the lived experience of people with Homozygous Familial Hypercholesterolaemia (HoFH) and their caregivers is now available also in Arabic, French, German, Italian and Spanish.

The results of the original survey (in English language) were presented as a poster at this year's [European Conference on Rare Diseases \(ECRD\)](#) conference.

For more information on the survey, developed by Ultragenyx, please see [Quality Of Life In HoFH Survey - FH Europe Foundation \(fhf.org\)](#).

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## Patient Engagement Open Forum

Patient Engagement Open Forum (PEOF) is the only global multi-stakeholder event dedicated to shaping the future of patient engagement. This unique platform brought together a dynamic community of multicultural and multidisciplinary visionaries, working together to create a brighter and healthier future for patients, with patients.

The in-person event took place from May 21 to 23 in Baveno, Italy. FH Europe Foundation was represented by our CEO, Magdalena Daccord, who attended to learn more about how to move

forward in our mission to drive lasting change in patient engagement. Participating was also our Sr Policy Advisor Nicola Bedlington and CEO of Global Heart Hub, our Network Member.

The forum featured engaging sessions, excellent speakers and a diverse program that offered valuable insights and discussions.

Read more about PEOF [here](#).



## PerMed FH Project meeting in Lyon

On Friday, May 24, the PerMed FH project consortium held its second in-person consortium meeting to review progress in the first 5 months and plan the next steps for this important research initiative.

The consortium's immediate task is to create educational materials for patients, emphasizing the importance of engagement in genetic research.

The project aims to clarify the genetics of Familial Hypercholesterolaemia (FH), to personalize diagnosis and treatment to improve patient outcomes. Led by Prof. Mafalda Bourbon and her team from Instituto Nacional de Saúde Doutor Ricardo Jorge, FH Europe Foundation's contribution is to provide patient perspectives, lead on information dissemination and education in the project, as education, awareness, trust, and consent are crucial for advancing innovation through sample collection and data sharing.

Read more about the project [here](#).



## Patient advocacy at the EAS Paediatric FH Symposium

On Saturday, May 25, 2024, three Patient Ambassadors from the FH Europe Foundation, alongside our CEO, made significant contributions at the 7th EAS Paediatric FH Symposium in Lyon, France. This event underscored the critical importance of integrating patient perspectives with scientific discourse to foster a comprehensive approach to awareness and management of familial lipid disorders early in the healthcare pathway, starting from childhood.

Our ambassadors, Jill Prawer, Danique van den Bogert, and Cindy Evans, presented their poignant personal experiences of living with Familial Chylomicronaemia Syndrome (FCS), Heterozygous

Familial Hypercholesterolaemia (HeFH), and Homozygous Familial Hypercholesterolaemia (HoFH) respectively. Their stories provided invaluable insights and underscored the human aspect of these conditions, deeply resonating with the audience.

Thank you to the organizing committee, led by Professor Steve Humphries, for their unwavering commitment to patient engagement. Their dedication ensures that patient voices are integral to the conversation, leading to enhanced medical education and ultimately better health outcomes for all.

The contributions of patient Ambassadors exemplify how patient narratives can enrich scientific presentations, fostering a holistic understanding of living with familial hypercholesterolaemia and related conditions.

Read more about the programme [here](#).



## Lp(a) International Task Force meeting in Lyon

On May 25 and 26, the Lp(a) International Task Force members, observers, and the FH Europe Foundation Team held an in-person meeting to discuss the status update of the 2024 work plan and significant content related to the initiative.

Since the last in-person meeting at ESC 2023 in Amsterdam, the group has expanded by gaining additional perspectives from health tech, innovation, patient advocates, and a new industry observer.



The two-day meeting was rich in topic-specific discussions, including education and awareness about Lp(a), health economics models for Lp(a) testing, applications of living labs, quality of life for people with high Lp(a), and the societal impact. Participants provided focused updates on the general situation in Europe, with detailed insights into Austria, China, and Japan. They also assessed the latest data on testing per capita across various countries. The crucial topic of defining primary vs. secondary prevention was also covered.

The meeting concluded with a specific set of agreed actions for the next six months and the year 2025.

Read more about this international project [here](#).



## FHEF at the EAS Annual Congress 2024

FH Europe Foundation's first booth and awareness raising at the EAS Congress 2024 was a major success and exceeded our expectations.

We engaged in exciting conversations about the lived experiences of those with familial lipid disorders such as HeFH, HoFH, elevated Lp(a), and FCS. Visitors shared their daily challenges,

including patient identification, screening, disease understanding, shared decision-making, treatment optimization, therapy access, and reimbursement.

We discussed the synergies between our work and the work of clinicians and scientists. Attendees learned about our leading research projects, including the PERFECTO project for FH pediatric screening and the PerMed FH precision medicine initiative for FH. We also highlighted the International Lp(a) TaskForce's efforts to drive policy change and make lipoprotein (a) measurement a standard of care. Our network of patient organizations across Europe and beyond was showcased, along with our awareness campaigns and advocacy work. Attendees discovered how meaningful patient engagement leads to better health outcomes and how their roles can make patient engagement happen.

The three days were intense but incredibly rewarding, thanks to our fantastic team – Cindy Evans, Emma Print, Marc Rijken, and Grainne Crowley – for their phenomenal work.

We appreciate everyone who stopped by to chat and share their experiences. It was a valuable opportunity to connect and collaborate for the benefit of all affected by familial lipid disorders.

*A special thank you to the European Atherosclerosis Society for collaborating with us on the Lp(a) testing booth, which attracted significant attention and traffic.*

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## **Advocating for HoFH at HealthTech for Patients Event**

Patient Ambassador Maria Nassif, participated in the HealthTech for Patients event on May 16, 2024, hosted by HealthTech for Care. She shared her journey with HoFH, highlighting mental health challenges and daily struggles of living with a chronic illness. Maria emphasized the need for early diagnosis, personalized treatment, universal access to care, effective communication with healthcare professionals, psychological support, and a strong patient community. Her participation underscores FH Europe Foundation's commitment to raising awareness and advocating for comprehensive patient care.

Read the full recap on Maria's contributions at the HTFP [here!](#)

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World Health Assembly 77  
Rare Diseases International Side Event



# Why invest in Rare Diseases?

## Ensuring UHC for PLWRD

**29 May 2024**  
**6-9 PM**

**Le Vieux Bois**  
**12, Av de la Paix**  
**Geneva, Switzerland**

### **Why invest in Rare Diseases? Highlighting the Importance of Rare Diseases at the World Health Assembly side event**

Another important event took place on May 29 in Geneva - a side event at the 77th World Health Assembly in Geneva, organized by Rare Diseases International with support from France and Malaysia. The event, titled "Why Invest in Rare Diseases?" aimed to demonstrate why investing in rare diseases is essential for promoting fairness for all people living with rare diseases (PLWRD).

The event advocated for a World Health Assembly resolution on rare diseases in 2025, which is important for gaining global support to prioritize rare diseases and improve access to diagnosis, treatment, and support for those affected worldwide.

As a patient organisation, covering both the most common genetic and inherited conditions in the world and the rare conditions of people living with familial hyperlipidaemias, we attended the event to highlight the challenges faced by people with rare and severe lipid disorders like HoFH and FCS.

Including the patient voice in these discussions is crucial for finding better solutions, as it can lead to improved health policies, stronger health systems, and more support for PLWRD and their families.

Read more about Rare Disease International [here](#).

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## **FHEF welcomes the EPP's pledge to improve cardiovascular health in Europe**

Ahead of the EU Parliament elections in June, the EPP Group, the largest and oldest group in the European Parliament, has pledged support for a cardiovascular disease plan in Europe. "We will launch a European Cardiovascular Health Plan, in response to the fact that cardiovascular disease is the biggest killer in the EU." [Watch the video](#) to hear about the Manifesto from Manfred Weber, President of the EPP Group.

FH Europe Foundation, as part of the EACH Alliance, is calling for a comprehensive policy response to improve the cardiovascular health of Europeans. Follow along and get involved on social media using [#VoteHealth2024](#).

To watch the video and to learn more visit <https://fhef.org/news/epp-manifesto/>.

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## **Spotlight on Rare Diseases: Unveiling Key Insights from the Europe Rare Disease Summit**

We are pleased to share the report from the Europe Rare Disease Summit with you. Back in February, Magdalena Daccord, our CEO and Grainne Crowley, our Partnerships and Development Lead from our team spoke at the event in Madrid hosted by Bamberg Health, in the context of rare familial lipid disorders. You can now dive into the pivotal ideas discussed by leading stakeholders across Europe, all dedicated to transforming the landscape of rare disease care and research. This comprehensive document captures the essence of collaboration, innovation, and the collective resolve to address the challenges faced by the rare disease community.

Access the full report [here](#).

## NETWORK NEWS



## Austria – FHChol

### FHChol at the Long Night of Research

During the Long Night of Research, an annual event where people can experience science up close, FHChol Austria participated in the cardiologists' booth at the Medical University of Vienna. They conducted lipid profile tests, measured blood pressure, and [generated AI-based risk profiles projecting up to age 80](#).

There was significant interest in the Lp(a) measurement, as it is not routinely tested in Austria, leaving many unaware of their levels. Many young people who had never had their cholesterol levels checked took advantage of the testing and counseling offer. Among the approximately 100 tested individuals, several had elevated Lp(a), and three cases of FH were discovered. The event was deemed very successful.

### VEGAN MEETS FH: A Culinary Experience at DAS Kochwerk

On Monday, May 13, 2024, a special cooking class, "VEGAN MEETS FH," was held at DAS Kochwerk in Vienna. Organized by FHChol, the event attracted numerous participants interested in healthy and delicious eating.

Under the expert guidance of dietitian Michelle Fuschlberger, a delightful FH-friendly vegan menu was prepared. The event was a great success, with participants enjoying various interesting dishes and receiving valuable recipes and tips for home preparation.

The menu began with a refreshing lentil salad, followed by a flavorful tomato soup. The main course featured a spicy curry served with homemade naan bread, and the meal concluded with a delectable strawberry cake.

Throughout the evening, participants asked numerous questions about vegan nutrition and its role in FH management. Dietitian Michelle Fuschlberger patiently answered all inquiries, providing valuable advice on dietary changes and optimization.

### **FHChol's FCS Online Meeting**

FHChol cordially invites you to the online FCS patient meeting with two exciting presentations on Tuesday, July 9, 2024, at 6:00 p.m. via ZOOM. This online meeting, organized by FHChol, features two lectures offering a valuable opportunity to learn more about FCS and share experiences and information with other FCS patients.

Univ. Prof. Prim. Dr. Elmar Aigner will present "Why do I have FCS and how do the symptoms develop?" followed by Mag.a Gabriele Skacel with "Delicious Better Food for FCS - Now It's Time to Cook Up!" This event provides a unique chance to gain insights into FCS management and nutrition. Participants are encouraged to register by July 5, 2024, at [info@fhchol.at](mailto:info@fhchol.at).

Read more about it [here](#).

*Prepared by FHChol Austria*

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## Croatia - Croatian Dyslipidemia Patient Organisation

The largest Croatian public health campaign for promoting awareness of CVD risk factors

The "Znaš li svoj broj?" (Do You Know Your Numbers?) campaign is Croatia's largest public health initiative aimed at raising awareness about the risk factors for cardiovascular diseases, which account for nearly half of all deaths in the country. The campaign particularly focuses on the dangers of high cholesterol, both hereditary (familial hypercholesterolemia) and lifestyle-related, which are often underestimated and unrecognized.

Approximately 60% of Croatia's population has higher than recommended cholesterol levels. To address this, the campaign features posters in public areas such as roadsides, tram and bus stations, pharmacies, and hospital waiting rooms. These posters include a QR code directing people to the [official campaign website](#), which provides comprehensive information about cholesterol and its risks.

In addition to the posters, the campaign includes monthly public events called "Hunting the silent killer," where citizens can receive free screenings for cholesterol, blood pressure, blood sugar, and body weight. These events aim to educate the public about their health numbers and encourage proactive health management. The campaign has been launched in Zagreb, Varaždin, and Samobor, with plans to expand to Osijek, Split, Rijeka, and Dubrovnik.

Read more about the campaign [here](#) (in Croatian language).

*Prepared by Croatian Dyslipidemia Patient Organisation*

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## **Estonia**

### **Living with FCS in Estonia**

On April 14, six-year-old Elisete Poobus, the youngest FCS ambassador in Estonia, and her family attended the 30th Anniversary conference of the Estonian Phenylketonuria Association. Elisete's mother, Teevi Poobus, shared their journey from diagnosis to daily management of Familial Chylomicronaemia Syndrome (FCS), highlighting the challenges of maintaining a strict diet with only 5g of fat per day for Elisete. Teevi expressed gratitude to healthcare professionals and discussed the absence of a dedicated FCS patient organization in Estonia.

In 2023, the family connected with the FH Europe Foundation, which provided much-needed support. Elisete and Teevi attended the Foundation's annual conference in Amsterdam, where they met other FCS patients. Their advocacy efforts have led to promising steps towards gaining recognition and support for FCS in Estonia.

Read more about it [here](#).



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## Hungary - SZÍVSN

### SZÍVSN's April Dedicated Education and Support

In April, SZÍVSN, the National Patient Association, hosted several impactful events to promote cardiovascular health and patient education. A highlight was the cardiology screening day with the SZTE Cardiology Center, where nearly 60 participants received personalized advice. The Cardiomyopathy Information Day introduced new medical advancements in Hungary, and Dr. Máté Vámos's lecture on smart heart rhythm monitoring devices enriched participants' understanding of modern healthcare technologies.

SZÍVSN also formed a specialized patient group for Hypertrophic Cardiomyopathy, with Péter Kovács as ambassador. Physiotherapist Gabriella Faragó highlighted the importance of rehabilitation, emphasizing empathy and humor in recovery, while the 345th SZÍVSN lecture explored post-rehabilitation pathways.

On April 28, 2024, the 50th cardiovascular screening event, supported by the Ministry of the Interior, Semmelweis University Városmajor Clinic, Rector Béla Merkely, and the Hegyvidék municipality, was held in a cultured environment with professional specialists. This event was part of SZÍVSN's spring initiatives, providing essential health services and fostering community, underscoring the organization's commitment to holistic patient care and education.

Read more about it [here](#).

*Prepared by SZÍVSN*

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## Ireland - Croí

### **Croí brings civil society and industry together to highlight urgent need for national heart strategy**

Croí, the Irish heart and stroke charity, has called for an urgent new national strategy to tackle cardiovascular health. This appeal is central to their newly launched manifesto, **'The Future of Cardiovascular Health in Ireland – A Manifesto for Change'** created in consultation with patient advocates, civil society organizations, professional bodies, and community groups. The manifesto outlines five key policy actions aimed at reducing heart disease and stroke in Ireland and easing the burden on healthcare. Cardiovascular disease is the leading cause of death and disability globally, claiming over 9,000 lives annually in Ireland, and accounting for 40% of hospital admissions and 75% of bed days. Ireland's last cardiovascular strategy expired in 2019 without renewal.

Croí is urging politicians to:

- Develop a comprehensive strategy similar to that for cancer.
- Set clear and measurable goals with a clear accountability framework.
- Allocate a multi-annual budget from the Department of Health.
- Appoint a dedicated policy lead.
- Establish a Cardiovascular Disease Prevention Implementation Taskforce.

The report states that, 'The national strategy needs to prioritise early detection, early diagnosis and early access to treatment and rehabilitation. This requires greater investment in screening and early detection across the life-course, especially for Hypertension, Atrial Fibrillation, Heart Valve Disease, and high Cholesterol. **In the context of high cholesterol, it is imperative that Ireland introduces a national screening programme for Familial Hypercholesterolemia (FH).'**'

Croí CEO, Mark O'Donnell, emphasized the importance of prevention, early detection, and risk management. Neil Johnson, Executive Director at the Global Heart Hub, and Croí Special Projects Advisor stressed the need for a proactive, community care-led approach to ensure equitable access to healthcare for all Irish citizens.

Read Croí's Manifesto [here](#).

*Prepared by Croí*

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## Italy - AISC

### AISC CELEBRATES ITS 10TH ANNIVERSARY

On April 10, 2024, AISC celebrated its 10th anniversary, embodying a decade of dedication, pioneering medical and scientific research, and unwavering patient support. To mark this milestone, AISC hosted the conference "Cardiac Failure Rehabilitation: A New Model Built on Patient Needs." This conference aimed to assess innovative rehabilitation techniques and propose a new therapeutic model tailored to patient needs. It provided a valuable platform for clinicians, rehabilitation experts, caregivers, patient representatives, and the scientific committee to explore various aspects of cardiac failure. Notably, a new model of cardiac rehabilitation centred on patient needs was introduced, signifying a significant advancement in patient care.

*Prepared by AISC*

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## Italy - ANIF

**In Europe, FH diagnosis occurs at age 44, and it is too late**

According to a study supported by FH Europe Foundation, at that age 17% already have cardiovascular disease; furthermore, the majority of patients do not reach the recommended therapeutic goals. “Every country should have a screening program for FH. These programs should be best adapted to the healthcare system of individual nations, starting from existing strategies. Furthermore, governments should provide financial support for screening programs and related treatments”, said Domenico Della Gatta, president of the Italian Association for Familial Hypercholesterolaemia (ANIF).

For a detailed exploration of this issue, refer to the article by Francesco Fuggetta published in "Osservatorio Malattie Rare" on the occasion of HoFH Awareness Day.

Read the full article [here](#).

*Prepared by ANIF*

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## **Latvia - Par Holesterinu**

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

Par Holesterinu is pleased to share the impact of Lp(a) Awareness Day 2024 in Latvia. This year marked the introduction of Lp(a) education for the first time in the country, addressing a critical gap in cardiovascular health awareness. With the support of cardiologists, essential information about Lp(a), including analysis recommendations and actionable steps for elevated levels, was provided. These achievements underscore the power of collaboration in advancing health education and empowering individuals to effectively address cardiovascular risks. Moreover, the campaign garnered widespread media coverage, amplifying its reach and impact.

Read more about it on their [website](#).

*Prepared by Par Holesterinu*

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## **Poland - EcoSerce**



### **Unwanted gifts – Workshop for Patients on Familial Hypercholesterolemia**

On May 18, 2024, the Medical University of Lodz hosted a workshop titled "Unwanted Gifts" for patients with familial hypercholesterolemia, organized by the Lipid Disorders Treatment Center at the Department of Internal Diseases and Clinical Pharmacology of the Medical University of Lodz and the Eco Serce Foundation. The event was led by FH patients. Patient priorities were discussed. Lectures were given by experts in the field of FH. Topics included perspectives from patients and doctors, genetic testing, and psychological aspects. A clinical dietitian provided dietary advice, and students conducted cholesterol level checks for attendees. Read more about it [here](#).

### **Meeting at the Polish Senate with discussion on the need for a systematic screening implementation for Familial Hypercholesterolaemia**

In Poland, EcoSerce took part in a crucial meeting at the Polish Senate, delving into the necessity of implementing systematic screening for Familial Hypercholesterolemia (FH). At the invitation of Senator Agnieszka Gorgon Komor, EcoSerce, along with Magdalena Daccord, the CEO of FH Europe Foundation, presented best practices in FH paediatrics screening and highlighted policy achievements like the Prague Declaration. The gathering brought together prominent figures in Polish cardiology, representatives from the Ministry of Health, children's rights advocates, and patient advocates, all emphasizing the urgency of prioritizing FH screening implementation. EcoSerce stressed the need for political commitment and support to prioritize FH child screening and

cardiovascular health prevention in Poland. The meeting showcased fantastic initiatives, underscoring the critical importance of advancing CVD prevention efforts in the country.

*Prepared by EcoSerce*

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## Global Heart Hub

### Global Heart Hub Reveals Insights into Unhealthy Cholesterol Management

The disparities faced by women worldwide in the diagnosis and treatment of heart disease are well-documented. Despite being the leading cause of death among women, heart disease remains understudied, under-identified, under-diagnosed, and under-treated.

On Monday, April 22, Global Heart Hub hosted a groundbreaking roundtable in Madrid, Spain, bringing together 27 participants from 15 countries. Attendees included women with firsthand experience, leaders of patient organizations, public health experts, researchers, and clinicians. The focus was on addressing late, missed, and misdiagnoses of heart disease in women.

[Read more about](#) it and [watch their video](#).

### Real-life data highlights need for patient-centered management of unhealthy cholesterol

Global Heart Hub presents initial findings from its patient-led Insights from Patients living with Elevated Cholesterol (IPEC) program. Revealed at ISPOR 2024, the data highlights barriers to patient-centered care in managing unhealthy cholesterol and emphasizes the need for holistic patient support.

Key findings from the U.S. include:

- Limited awareness of cardiac risks associated with high LDL-C.
- Prioritization of managing co-occurring conditions over cholesterol management.
- Challenges in diagnosis and adherence to treatment due to various factors.

Neil Johnson, Executive Director of Global Heart Hub, stresses the importance of integrating patient perspectives into LDL-C management strategies to combat ASCVD effectively.

Celina Gorre, Chief Executive Officer of WomenHeart, underscores the necessity of including the patient voice in decision-making processes to enhance care and outcomes.

Read more about it [here](#).

# Understanding the Link Between Obesity and Cardiovascular Disease

**Prof Carel le Roux**  
Director of the Metabolic Medicine Group University College Dublin

**Susie Birney**  
Executive Director Irish Coalition for People Living with Obesity

**Claire Flower**  
Patient Advocate

**Vicki Mooney**  
Executive Director European Coalition for People Living with Obesity

Monday, June 24 | 10:30 EST | 14:30 UTC | 15:30 IST | 16:30 CET | Join Us!



## Global Heart Hub Empower Webinar: Understanding the Link Between Obesity and Cardiovascular Disease

Global Heart Hub is excited to announce their upcoming Empower Webinar, focusing on the critical connection between obesity and cardiovascular disease. Scheduled for June 24, 2024, at 16:20 CET, this event is organized in collaboration with the Irish Coalition for People Living with Obesity (ICPO) and the European Coalition for People Living with Obesity (ECPO).

The webinar will feature Professor Carel le Roux from University College Dublin, who will discuss obesity as a disease, its link to cardiovascular disease, risk factors, and patient management. A patient panel, including ICPO Executive Director Susie Birney and advocate Claire Flower, will share

their experiences, highlighting issues of stigma, bias, and healthcare silos. ECPO's Executive Director Vicki Mooney will then discuss recent healthcare developments and their implications for patients.

This is an excellent opportunity for those affected by or interested in obesity and cardiovascular health to gain insights and engage with experts.

To learn more and register, click [here](#).

*Prepared by Global Heart Hub*

**PATIENT  
STORIES**

My story  
of living with  
H<sub>2</sub>FH

**Marwa Sadeek from the UK**





## My story of living with HoFH

Meet Marwa, a vibrant 38-year-old from London, who juggles her roles as a medical interpreter, a psychology degree holder, and a devoted mother of two girls. Diagnosed with Homozygous Familial Hypercholesterolaemia (HoFH) at the age of three, Marwa's life has been intertwined with hospital visits and treatments. Read about the challenges she was and is facing in education, employment, and personal relationships due to the rarity of her condition and why she emphasizes the importance of awareness and early diagnosis for HoFH, advocating for a brighter future for those affected. Marwa's story is a testament to hope and the transformative power of medical advancements. Join her on May the 4th to unite for HoFH awareness.

Read the full story [here](#).

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**PARTNER**  
**NEWS**

## EURORDIS

### Open Letter to the European Commission: Urgent Call to Action from ECRD 2024

The European Conference on Rare Diseases and Orphan Products (ECRD) stands as Europe's foremost patient-led event dedicated to shaping rare disease policies. By uniting individuals with rare diseases, patient advocates, policymakers, healthcare industry representatives, clinicians, regulators, and Member State representatives, EURORDIS leverages the collective strength of this network to craft forward-thinking policies.

Reflecting the goals discussed during the 12th ECRD sessions, FH Europe Foundation's Ambassador, representing HoFH and FCS, supported the co-creation of an Open Letter to the European Commission. This letter urges the next wave of European leaders to:

- **Prioritize health** in all upcoming policies and programs.
- **Formulate a robust European Action Plan for Rare Diseases**, one that integrates various policy areas and aligns existing efforts with clear, measurable goals.

- **Promptly address the critical needs of the rare disease community** by incorporating the feasible actions we've identified into the upcoming work programs.

You can read the full letter [here](#).

We encourage you to join the rare disease community in amplifying this call by signing the petition [HERE](#).

### **New Guide to developing a Patient Journey published!**

Patient Journeys are invaluable service improvement tools that offer a comprehensive view of rare conditions through the lens of those living with them. They capture the natural history of a condition and the day-to-day experiences of patients, identifying common unmet needs and guiding actions to address them.

This Guide, crafted by EURORDIS in collaboration with patient representatives and clinicians from European Reference Networks (ERNs), provides step-by-step guidance, practical tips, and tools for developing Patient Journeys. It empowers patient representatives within ERNs to engage with their communities, map needs, and inform care pathways based on real-life experiences.

You can read the full guide [here](#) and watch the webinar on this theme it [here](#).

### **EURORDIS Survey: Strong Backing for Newborn Screening in Rare Diseases**

EURORDIS-Rare Diseases Europe presents findings from its survey on newborn screening for rare diseases, shedding light on robust support for early diagnosis within the rare disease community. With 73% of respondents advocating for early diagnosis at birth and 90% endorsing newborn screening, the results underscore the pressing need for enhanced screening programs throughout Europe.

Virginie Bros-Facer, CEO of EURORDIS, emphasizes the importance of these findings, stating, "Early detection is crucial in addressing rare conditions, improving healthcare follow-up, and preventing further complications. Our 11 Key Principles for Newborn Screening, established in 2021, aim to ensure the highest health standards for all newborns."

The survey report and detailed results will be available in English, with additional factsheets in 15 languages, ensuring broad accessibility. Learn more on the Rare Barometer website.

Read more about it [here](#).

## **EURORDIS' Survey Reveals Lengthy Diagnostic Delays for Rare Disease Patients**

EURORDIS has released findings from a significant Rare Barometer survey, uncovering prolonged diagnostic journeys endured by rare disease patients across Europe.

Conducted from 17 March to 15 June 2022, the survey engaged over 10,000 patients from 42 countries, representing 1,675 rare diseases.

Jessie Dubief, Social Research Director at EURORDIS, highlights the survey's revelations: "The findings reveal an average diagnostic journey of nearly five years, with notable disparities based on demographics and geography. Women and young patients endure longer waits, underscoring the need for tailored approaches to improve diagnosis rates and reduce waiting times."

Virginie Bros-Facer, CEO of EURORDIS, emphasizes the urgency of addressing diagnostic delays: "Unacceptable delays compromise patient care and quality of life. Every day without a diagnosis is a day lost. We must close the gap in diagnostic services, ensuring timely access to accurate diagnoses for all patients."

### **Key Findings:**

- **Lengthy Diagnostic Wait:** The average rare disease patient waits 4.7 years for a diagnosis, with 25% requiring eight or more consultations before confirmation.
- **Misdiagnosis Challenges:** 60% of patients initially face misdiagnosis, prolonging suffering and complicating treatment.
- **Gender and Age Disparities:** Women and children experience longer diagnostic waits, highlighting the need for targeted interventions.
- **Role of Expertise Centers:** Patients referred to Centers of Expertise experience shorter diagnostic journeys, emphasizing the need for increased referrals.

EURORDIS advocates for policy action to improve diagnostic pathways in Europe. The #ActRare2024 campaign focuses on promoting earlier, more accurate diagnosis and outlines policy recommendations for EU policymakers.

Read more about it [here](#).

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## European Patients Forum

### EPF's Leadership Event and AGM 2024: Advocating for Patients

The European Patients' Forum (EPF) recently hosted a dynamic Leadership Event and Annual General Meeting (AGM). The event featured a workshop on Artificial Intelligence (AI) in healthcare, followed by the AGM. Discussions included AI literacy for patient advocacy and responsible AI use. The AGM saw approval of the 2023 Annual Report, financials, and 2024 work plan. Four new Board members were elected, and EPF welcomed two new associations as full members. The day concluded with a discussion of EPF's #Vote4Patients 2024 EU Elections Campaign, highlighting campaign progress and achievements.

Read more about it [here](#).

### European Patients' Forum Receives Operating Grant to Advance Patient Advocacy

The European Patients' Forum (EPF) has attained an operating grant under the EU4Health Programme for 2024, signifying a pivotal step forward in its mission to propel patient advocacy efforts throughout Europe.

This grant will bolster EPF's multifaceted initiatives, encompassing policy advocacy, awareness campaigns, membership support, capacity building, and communication endeavors. Notable areas of emphasis include advocating for legislative initiatives, raising awareness on pressing global health issues, engaging patients in regulation implementation, conducting vital capacity building activities, and intensifying communication efforts.

EPF's overarching goal is to shape and fortify the European Health Union, ensuring it effectively addresses the needs of patients and citizens alike by facilitating robust patient involvement in EU policies, legislative processes, research endeavors, and relevant EU actions.

Read more about it [here](#).

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## World Heart Federation

### World Heart Day 2024: Exclusive Launch Event Invitation

Mark your calendars for the World Heart Day 2024 launch event on Thursday, June 20, at 14:00 CEST. This event will unveil the new campaign theme, resources, and activities, inviting everyone to join the mission of promoting heart health.

Cardiovascular disease remains the leading cause of death worldwide, claiming over 20 million lives annually through heart attacks, strokes, and heart failure. World Heart Day serves as a global reminder to prioritize heart health. This year's campaign emphasizes the right to cardiovascular health for all, advocating for universal access to heart health education, resources, and care.

Register and learn more [here](#).

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**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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