FH Europe
Foundation

Cardiovascular Prevention as the Cornerstone of a Competitive Europe

Scaling Up Lipid Screening to Secure Next Generations

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EVENT REPORT

Foreword

By Magdalena Daccord,

Chief Executive Officer, FH Europe Foundation

“Ten years ago, a small group of European advocates, patients living with familial hypercholesterolaemia (FH), clinicians and researchers, entered the European Parliament carrying stories of loss, determination, and a simple message: **cardiovascular disease is preventable, if Europe chooses prevention**. That moment marked the beginning of a movement.

From the **2015 Call to Action on FH**, which first urged the creation of an EU strategy for cardiovascular prevention, to the **Prague Declaration on Paediatric Screening (2022)** and the **Brussels International Declaration on Lipoprotein(a) (2025)**, our Network has transformed lived experience into system change. What began as **FH Europe**, a small patient-led charity, has evolved into the **FH Europe Foundation**—a trusted partner in European and global health policy, a convener of science, advocacy and innovation, and a united voice for families affected by inherited lipid disorders. Today, our network spans **36 member organisations across Europe**, joined by partners and ambassadors from the **Middle East, Asia, Australia, China, Singapore, and the United States**, as well as one global organisation representing the international **familial hyperlipidaemias** community, beyond FH.

Over the past decade, our advocacy has helped make **paediatric FH screening** a reality across several EU countries, inspiring action, implementation, and policy change. Today, more and more nations screen not only for **cholesterol but also for lipoprotein (a)**, addressing both known and emerging risks. Our collective efforts have **improved access to treatment**, especially in regions where therapies were previously unavailable. We have **helped establish patient communities, and empowered ambassadors to advocate, speak up and co-design solutions**, ensuring that lived experience shapes the future of cardiovascular prevention and care.

Our community has shaped national and EU agendas, forged alliances with clinicians, researchers and policymakers, and contributed to the recognition of **paediatric FH screening as an EU Best Practice on Public Health**. We have joined leading coalitions and collaborated with **European institutions, national governments and the World Health Organization**, including recent high-level meetings with the **European Commissioner for Health**. Through research consortia such as **PERFECTO FH**, **FH-EARLY**, and **PerMed FH**, patients have become **co-creators of innovation**, guiding research, implementation, and policy. We have **convened the first Lp(a) Global Summit**, **launched International HoFH Awareness Day**, and **initiated the first-ever international cost-effectiveness study of Lp(a) testing and management in primary prevention**, transforming advocacy into evidence and global impact.

> ***“From the Prague and Brussels Declarations to the Commission’s Call for Evidence, patient voices have shaped policy like never before.”***
>
> **Magdalena Daccord,**
> CEO, FH Europe Foundation

This event, *Cardiovascular Prevention as the Cornerstone of a Competitive Europe - Scaling up Lipid Screening to Secure Next Generations*, embodies that journey. It demonstrates how science, policy, and lived experience can converge into one collective purpose: **to prevent the preventable**.

As a proud member of the **European Alliance for Cardiovascular Health (EACH)**, the FH Europe Foundation is driven by a clear mission, to ensure that cardiovascular prevention as well as care for **rare diseases**, become a defining pillar of Europe’s health and competitiveness. Now is the time to act with courage and conviction. The forthcoming **EU Cardiovascular Health Plan** must become the **best possible policy blueprint** not only for the European Union but for the rest of the world. It must demonstrate that **prevention is a right, not a privilege**.

We must use every tool, every partnership and every piece of evidence to **bridge science and society**, to close gaps in access and awareness, and to uphold the **right to health for all**, regardless of age, sex, race, socio-economic background, or postcode. **No one should be left behind**.

When we look back, we see resilience—a decade of unity, persistence, and progress. When we look ahead, we see possibility—a Europe ready to lead with compassion and ambition. Together, we can **turn declarations into delivery, research into reality**, and **commitment into care**.

The time for action is now. Together, we can prevent the preventable and make cardiovascular health the foundation of a competitive, equitable and compassionate Europe.”

Executive Summary

Cardiovascular Prevention as the Cornerstone of a Competitive Europe

Cardiovascular disease (CVD) is still Europe's leading cause of death, responsible for **one in three lives lost**[1] **and costing €282 billion every year**[2]. Yet most of this burden is preventable. The event, organised by **FH Europe Foundation** and co-hosted by Members of the European Parliament (MEP) Romana Jerković and Tomislav Sokol, united patients' testimonials, scientific evidence, and policy momentum into a single call: make prevention Europe's competitive advantage!

Held just one day after familial hypercholesterolaemia (FH) awareness day (24 September) and attended by over **250 people** in-person and online, the event also marked the culmination of ten years of advocacy: from the 2015 Call to Action[3] to Prague Declaration (2022)[4,5] and Brussels Declaration (2025)[6,7] to FH Europe Foundation's Response to the Commission's Call for Evidence[8] to the start of Europe's first Cardiovascular Health Plan.

Patient Voices at the Heart of Prevention

Globally, a child with FH is born every minute,[9] **and 1 in 5 individuals have elevated lipoprotein(a) [Lp(a)]**[7]. At the European Parliament, families and young patients from across Europe shared deeply personal stories that turned numbers into faces and futures: a young Austrian woman wishing that everyone could be screened for FH and diagnosed as young as she was, a Dutch male student whose Lp(a) result changed his life trajectory in a positive health-oriented way, a Polish woman living with a rare and severe form of FH, which claimed the life of young sister before the two ever met, due to lack of treatment for homozygous FH (HoFH) and a mother from Estonia caring for a child with familial chylomicronaemia syndrome (FCS)—a rare lipid disorder.

Their message was a united and urgent call: screen early, treat equally, and act collectively. Their stories of early diagnosis, loss and resilience were repeatedly described by participants as "*the most powerful part of the event," praised for bringing "the human face of policy.*"

Science, Economics, and Declarations Align

Researchers and medical experts Prof. Nordestgaard, Prof. Wiegman and Prof. Kronenberg demonstrated that universal paediatric screening combined with cascade and reverse cascade screening for FH and one-time lifetime testing for lipoprotein(a) are **clinically effective**[4,5,10], while Prof. Ademi proved that those methods are cost-saving. When we speak about FH, for example, every €1 invested in screening results in up to €8 in return[11,12].

Participants valued these presentations for their **clarity**, **reliability** and **relevance**, underscoring the role of evidence and data in sustaining political will.

From Research to Real-World Solutions

Speakers from the European projects **PERFECTO FH**, **FH-EARLY**, and **PerMed FH** showcased how cutting-edge innovation is transforming prevention and care for FH[13-15]. Together, these initiatives demonstrate how personalised communication, artificial intelligence, paediatric screening, and genomic medicine can be integrated into real-world health systems to improve early detection, risk stratification, and patient outcomes, while offering synergies and potential solutions to scale up across all lipid disorders.

The atmosphere throughout was one of momentum and purpose. Nearly every respondent to FH Europe's post-event survey found the session **both personally and professionally relevant**, reflecting the shared conviction that cardiovascular health is not a niche agenda but a European imperative.

FH Europe Foundation policy asks

Building on the Prague Declaration[4,5] and the Brussels International Declaration[6,7]—to embed systematic early and equitable screening for familial lipid disorders, including paediatric FH screening, once-in-a-lifetime Lp(a) testing and early detection of rare forms in the EU Cardiovascular Health Plan.

Cardiovascular Health: A Strategic Imperative for Europe

Cardiovascular disease causes one in three deaths across the European Union[1], with more than 1.7 million lives lost each year[2]. It costs €282 billion every year which is equivalent to 2% of the EU GDP[2]. Of this, €155 billion falls directly on health and social care systems, while productivity losses from premature death and illness reach €48 billion[2]. Coronary heart disease alone accounts for over a quarter of that total[2].

These figures translate into real human and social costs: children losing parents too young, workers leaving the labour force prematurely, health systems stretched by late-stage disease. Studies show that Europeans living with CVD are **2.5 times more likely to receive disability benefits** and **one-third more likely to retire early than their healthy peers**[16], shrinking Europe's productive workforce at a time when ageing populations and staff shortages already threaten healthcare capacity.

Furthermore, the burden is not equally shared. Mortality from heart disease and stroke remains up to **13 times higher among women in Lithuania than in France**, and the *2023 ESC Atlas of Cardiovascular Disease* shows that while high-income EU countries have cut CVD mortality by over 50% since 1990, middle-income countries have seen declines of less than 12%[17,18]. This gap mirrors health-system inequalities that prevention can close.

Inherited lipid disorders, including **both forms of FH (HeFH and HoFH)**, elevated Lp(a), and FCS, illustrate both the challenge and the opportunity. Despite affecting around **90 million Europeans**, fewer than **10%** of FH cases are diagnosed[5,7]. FH is typically detected at **44 years of age**, and by then **17% of patients have already suffered a heart attack**[19]. Half of men with FH will have an event by 50; a third of women by 60[19]. Earlier identification through paediatric and cascade screening could rewrite this timeline entirely.

Hence, the European Parliament meeting, *Cardiovascular Prevention as the Cornerstone of a Competitive Europe - Scaling up Lipid Screening to Secure Next Generations*, framed prevention not as a medical issue alone but as the basis of economic and social resilience.

> ***"Without healthy citizens, there is no productive workforce. Without healthy children, no competitive next generation."* Romana Jerković, MEP**

The Council Conclusions on Improving Cardiovascular Health in the European Union (2024)[20] gave these facts political weight. The Conclusions explicitly name **inherited lipid disorders** among key metabolic risk factors, recognising that elevated cholesterol, whether acquired or genetic, demands systematic prevention, early detection and adequate treatment.

As the European Commission finalises the first **EU Cardiovascular Health Plan**, stakeholders agreed that prevention must anchor Europe's competitiveness agenda.

The Human Face of Policy: Patient Testimonies

If policy begins with evidence, change begins with experience. At the heart of the event were five voices, each a poignant lived reminder that prevention is not a concept but an imperative choice. Their testimonies spoke louder than any graph or budget line: screening saves lives, access saves futures, and attention saves hope.

Patient stories opened the session, reminding policy-makers that there is a person, a family behind every statistic, whose life changed due to delayed diagnosis. While each voice was different, their message was common: **screen early, treat equally, and act collectively**.

"Their testimonies are more powerful than any speech we deliver"

Romana Jerković, MEP

"Early diagnosis should not depend on tragedy, and it should not depend on luck."

Lena-Rosa Hanauer (Austria)

When her father suffered a heart attack at 30 and was diagnosed with FH, it set off a search for answers. Tests revealed that two-year-old Lena-Rosa also had FH, but unlike her father, her journey began with prevention, not crisis. That difference, early versus late detection, separated survival from tragedy. Today, Lena-Rosa studies genetics, determined to ensure that no family must repeat their story. Her experience embodies the message that prevention must begin early and generationally.

! **Policy insight:**
Systematic paediatric testing for FH should be standard across all EU Member States.

"Screening gave me direction, not fear."

Aedan Kaal (The Netherlands)

Aedan's story spans four generations of inherited lipid disorders, from his great-grandmother's undiagnosed cholesterol signs to his own early testing as a child. He was tested early for FH and results came back negative; however, they revealed elevated Lp(a). That early insight changed his trajectory and also that of the entire family since the family has been double hit by FH and high Lp(a); now a medical student, Aedan, stands between two worlds, the clinic and the patient community.

! **Policy insight:**
Integrate once-in-a-lifetime Lp(a) testing into all national cardiovascular screening programmes.

“Access should not depend on where you live.”

Joanna Kacprzak (Poland)

Joanna was born into a family already marked by loss: her sister died at 13 from a heart attack due to undiagnosed HoFH, a severe, rare form of FH. Years later, Joanna is born with the same condition but in a new era of therapy and awareness. Modern treatment transformed her health, but she knows others still wait for the same chance. Her story is a reminder that innovation without equitable access leaves patients behind.

! **Policy insight:**
Ensure equitable access to life-saving lipid-lowering therapies across all EU countries.

“Rare counts too. Don’t forget us.”

Teevi Poobus (Estonia)

Teevi is the mother of Elisette, the only known child in Estonia with FCS. Their daily routine is shaped by vigilance: strict, drastically low-fat diet, fear of pancreatitis, hospitalisation and CVD later in life, and a health system unprepared for ultra-rare conditions, like FCS which affects 1–2 individuals per million people. Her message to policy-makers was simple: recognition is care.

! **Policy insight:**
Integrate rare lipid disorders and caregiver support within the EU Cardiovascular Health Plan and national frameworks.

“There were so many points in this patient journey that were simply missing.”

Madalina Iamandei (Romania / Belgium)

Moderator and advocate, Madalina closed the testimonies with her own family story. Her father’s FH was diagnosed too late, only after multiple cardiac events; she herself was identified years later, in another country. Her remarks emphasise the need for Europe to close the diagnostic gaps that cost time and lives.

! **Policy insight:**
Lipid disorders awareness and digital health systems can prevent missed diagnoses and, thereby, save lives.

Prevention pays off

These stories carried the emotional truth of prevention: that a diagnosis delayed is a future denied by losing decades of prevention. Together, they laid the foundation for the next conversation about how evidence and economics confirm what patients already know: prevention pays.

Ten years on: From Lived Experience to System Change

From 2015 to 2025, FH Europe Foundation has worked relentlessly to turn lived experience into policy evidence. This decade produced three landmark achievements.

In her keynote intervention, **Magdalena Daccord**, CEO of FH Europe Foundation, reflected on a decade that began with patient communities asking for recognition and ended with cardiovascular prevention standing firmly on the EU policy agenda.

Magdalena reminded participants that progress did not happen by chance. It came through patient persistence, scientific partnerships, and constructive dialogue with policy-makers across successive EU presidencies. The Prague Declaration on FH Paediatric Screening (2022)[4,5] and Brussels International Declaration on Lp(a) Testing and Management (2025)[6,7] and FH Europe Foundation's response to the European Commission's Call for Evidence (2025)[8], collectively built a foundation of trust and expertise that now underpins the forthcoming **EU Cardiovascular Health Plan**.

She called the **next decade one of delivery**: implementing what the evidence already proves and ensuring that patients remain partners, not beneficiaries, in prevention. The transition from advocacy to action, she argued, must be guided by the same lived experience that fuelled the first ten years of change.

Her message was clear: Europe now has the science, the tools, and the political momentum. The challenge ahead is execution, by embedding cardiovascular prevention into national health systems so that no diagnosis, and no life, depends on chance.

The Case for Action: Data, Economics and Policy Tools

Screening and Testing Pays Off

Prof. Zanfina Ademi, Monash University, AustraliaAustralia

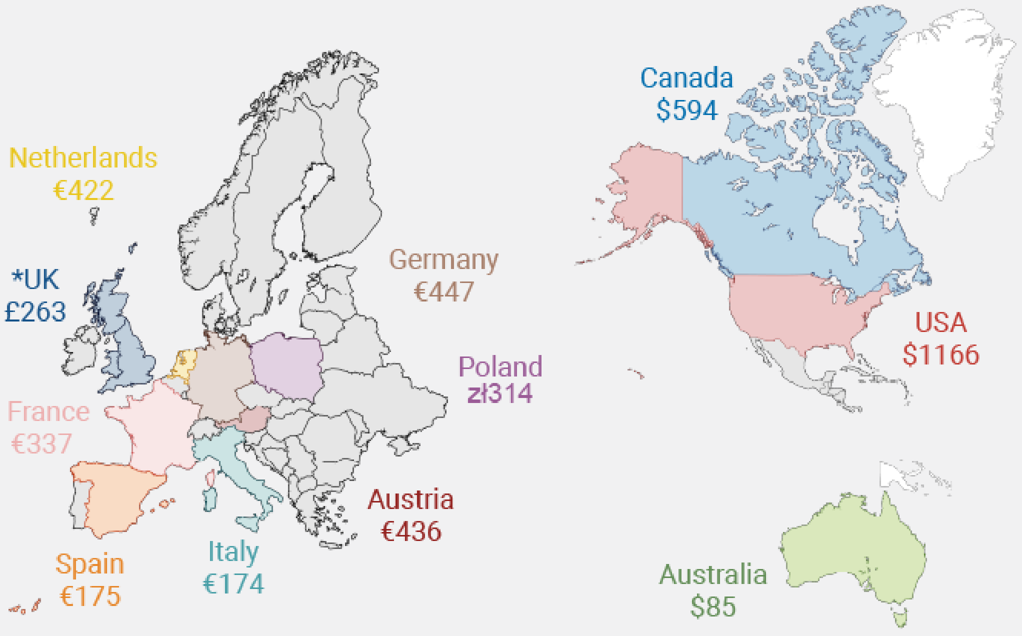
Prof. Zanfina Ademi of Monash University and member of the Lp(a) International Taskforce, highlighted compelling economic evidence demonstrating that screening and testing for **FH and elevated Lp(a)** represent **highly cost-effective and often cost-saving strategies** for cardiovascular disease prevention[10-12]. She emphasised that identifying high-risk individuals early not only prevents premature cardiovascular events but also substantially reduces long-term healthcare expenditure and societal burden.

Drawing on data from multiple international studies, Prof. Ademi underscored that **cascade screening for FH**, testing first and second-degree relatives of an index case consistently delivers the greatest economic value. This approach yields high detection rates due to the hereditary nature of the condition, carries minimal marginal testing costs, and produces significant lifetime quality-adjusted life year (QALY) gains through timely initiation of lipid-lowering therapy. **Universal or opportunistic child screening**, when followed by cascade testing in families, was also shown to be cost-effective or cost-saving, as early LDL-C (low-density lipoprotein cholesterol) reduction prevents decades of exposure and unlocks multiple undiagnosed cases. In adults, integrating FH screening into primary care settings further enhances cost-effectiveness, especially when positive results automatically trigger family tracing.

Citing evidence from **the Netherlands**, Prof. Ademi presented a 20-year national cascade screening programme that identified over **26,000 FH carriers**, including **5,600 children**, and achieved an average gain of **2.53 QALYs per person** at an incremental cost-effectiveness ratio of **€9,220 per QALY**, well below the national threshold of €20,000. The programme proved cost-saving from a societal perspective, generating an **estimated €8.37 return for every euro invested** through reduced premature heart attacks, hospitalisations, and productivity losses[11,12].

Turning to **elevated Lp(a)**, Prof. Ademi highlighted that **once-in-a-lifetime testing** in adults is similarly cost-effective and, in many cases, cost-saving[10]. Since Lp(a) levels are genetically determined and stable throughout life, a single test provides lifelong risk information and supports more targeted prevention strategies. Results from a **multinational health-economic analysis across 11 countries** showed that universal Lp(a) testing in primary prevention could prevent **60 first heart attacks, 13 strokes, and 26 premature deaths per 10,000 individuals**, while reducing healthcare costs by **€75–450 per person**[10]. Approximately **20% of adults** were reclassified into higher-risk categories, prompting earlier and more intensive management, and improving population-level cardiovascular outcomes.

In conclusion, Prof. Ademi stressed that **early, targeted screening and testing for inherited lipid disorders** are among the most **cost-effective cardiovascular prevention interventions available**. These approaches deliver substantial health gains, generate economic returns, and contribute to more efficient and equitable healthcare systems across Europe.



Cost saved per person from societal perspective (healthcare and indirect costs due to productivity losses)

Adapted from Morton JI et al. Atherosclerosis. 2025;409:120447

The tale of two declarations

— **Prof. Børge Nordestgaard**, President of the European Atherosclerosis Society (EAS)

Opening the session, **Prof. Børge Nordestgaard** laid the scientific foundation for understanding the four major lipid disorders and their profound impact on cardiovascular health. Speaking in his capacity as President of the European Atherosclerosis Society, he reminded participants that **elevated lipids remain the leading cause of CVD**, responsible for one in three deaths in the EU and costing European health systems an estimated **€282 billion annually**[2]. Most of these diseases, he stressed, are preventable through early lipid testing and effective lipid-lowering treatments[10-12].

Prof. Nordestgaard reviewed the long-standing scientific leadership of the EAS and its close collaboration with the European Society of Cardiology (ESC), tracing the joint publication of dyslipidaemia guidelines back to 1994. He announced that this collaboration continues with the **2025 Focused Update of the 2019 ESC/EAS Guidelines for the Management of Dyslipidaemias**, aimed at deepening clinical reach and impact among cardiologists across Europe[21,22].

Drawing on extensive evidence from population studies in Denmark, he illustrated how early diagnosis and treatment of lipid disorders can **prevent premature cardiovascular disease and death**, and yield substantial savings in national health budgets. His presentation outlined the genetic and metabolic mechanisms underlying **FH, elevated triglycerides, remnant lipoproteins, and Lp(a)** all of which can now be detected easily and managed effectively with modern therapies such as statins.

He emphasised that **FH is an inherited, fully preventable cause of premature CVD**, noting that simple, inexpensive screening starting in childhood or early adulthood can identify at-risk individuals and their relatives. His vision for Europe is an “***ideal screening model***”, where every citizen receives a **full lipid profile** early combining it with other interventions like vaccinations in childhood.

Prof. Nordestgaard concluded with a compelling call to action: “***Why wait for disease, when we can prevent it early, easily, inexpensively, and effectively?***” His message reinforced that the integration of systematic lipid screening and preventive care into European health systems is not only feasible but essential for reducing the continent’s cardiovascular burden.

The Prague Declaration[4,5] calls for:

- **Political leadership** to make FH paediatric screening a national reality;
- **Investment and policy frameworks** to raise awareness among clinicians and the public;
- **Comprehensive early detection** and life-course care programmes in every EU Member State;
- **Capacity building and patient empowerment** to strengthen community advocacy; and,
- **Shared learning and monitoring** across Europe.

— **Prof. Albert Wiegman**, Amsterdam University Medical Center; Trustee of FH Europe Foundation , Co-author of the Prague Declaration on FH Paediatric Screening

Building on decades of clinical experience and research in paediatric lipid disorders, **Prof. Albert Wiegman** delivered a powerful call to action for **systematic, early identification of familial FH in children**. Long before the Prague Declaration, his pioneering work in the Netherlands established FH cascade screening as a practical, evidence-based public health measure, providing further evidence that early treatment and early childhood screening profoundly improve long-term outcomes.

Prof. Wiegman reminded participants that **two children with FH are born each day in the Netherlands, and eight in Germany**, yet only around **10% of all individuals with FH in Europe are diagnosed**[23]. He presented compelling clinical evidence demonstrating that **early detection and lipid-lowering therapy in childhood prevent premature cardiovascular disease**, noting that the median age of FH diagnosis remains far too late - around 44 years[11,12,23]. His message was clear: "***To treat those with FH early, we have to find them early***."

Reflecting on his role in developing the The Prague Declaration on FH Paediatric Screening (2022)[4,5] led by FH Europe, Prof. Wiegman described it as a guiding framework, a **"North Star"**, for European health leaders committed to prevention. He recalled how the Declaration, born out of collaboration between experts, policy-makers, and patient advocates, was formally recognised by the **EU Public Health Best Practice Portal in 2021** and discussed at **high-level EU meetings in Slovenia (2021)** and the **Czech Senate (2022)**. He reviewed the **key calls to action** of the Prague Declaration.

Prof. Wiegman showcased the growing **coalition of support** for the Declaration from European institutions, governments, professional societies, and patient organisations, demonstrating a broad consensus that FH paediatric screening is a **life-saving, cost-effective, and ethically imperative intervention**.

Wrapping up his message with warmth and humour, he shared his Five Golden Rules, a set of simple but powerful and optimistic habits for a lifetime of good heart health.

He closed by inviting the audience to **revisit the Prague Declaration**, reaffirming its relevance and urging policy-makers and health leaders to turn its vision into practice. His concluding message was both urgent and hopeful: t**he science is settled, the evidence is clear, and now is the time to ac**t.

Five Golden Rules

by Albert Wiegman:

1. Eat your vegetables
2. Take your medicine
3. Exercise regularly
4. Never smoke
5. ALWAYS look left and right before crossing the road! (in the UK, the other way around!)

— **Prof. Florian Kronenberg**, Medical University of Innsbruck; Chair of the Lp(a) International Task Force

Prof. Florian Kronenberg introduced the work of the **Lp(a) International Task Force (ITF)**, underlining that **high Lp(a)** is one of the strongest yet most under-recognised risk factors for cardiovascular disease. Affecting **one in five people worldwide**, an estimated **1.4 billion individuals**, and more dangerous than LDL-cholesterol, Lp(a) remains **largely undiagnosed**, with only **1–2 percent** of Europeans and global population ever tested[7]. Prof. Kronenberg described this as a "silent, inherited threat" of enormous public-health relevance, noting that elevated Lp(a) in combination with traditional risk factors such as smoking, diabetes, or hypertension multiplies lifetime CVD risk several-fold[7].

As Chair of the Brussels International Declaration on Lp(a) Testing and Management (2025)[6,7], he set out its vision to make Lp(a) testing a standard component of **European cardiovascular prevention and health policy**.

Prof. Kronenberg emphasised that these measures are not aspirational but **economically sound**, aligning with evidence that **once-in-a-lifetime Lp(a) testing is cost-effective or cost-saving** by enabling early risk reclassification and targeted prevention. He underlined that investing in systematic prevention yields dividends in healthier populations, reduced CVD mortality, and more efficient health systems.

The Brussels International Declaration has already attracted **remarkable political and institutional endorsement**. Prof. Kronenberg highlighted statements of support from **European Commissioner Oliver Várhelyi**, who linked the initiative to the forthcoming **European Cardiovascular Health Plan**, and from MEP Romana Jerković, who urged policy-makers to incorporate the Declaration's principles into EU legislation. With **over 700 signatories from experts, organisations, and citizens**, he described the Declaration as "a movement that can no longer be ignored."

Closing his intervention, Prof. Kronenberg called for collective commitment to integrate Lp(a) testing into Europe's prevention agenda, stressing that **high Lp(a) is the next major frontier in cardiovascular risk reduction**—and that, with political will, testing and management could soon become a routine, life-saving standard of care across all Member States.

The Brussels International Declaration calls for:

- **Systematic inclusion of Lp(a)** in national and European Cardiovascular Health Plans;
- **Policy frameworks and reimbursement schemes** ensuring access to once-in-a-lifetime Lp(a) testing and follow-up care;
- **Integration of Lp(a)** into comprehensive cardiovascular risk assessment across all age groups; and,
- **Political leadership** and sustained awareness-raising to translate scientific consensus into public-health action.

Linking the Council Conclusions and the Cardiovascular Health Plan

Kitti Almer, FH Europe Foundation's Policy and Advocacy Manager

FH Europe Foundation's Policy and Advocacy Manager, **Kitti Almer**, explained how the Council Conclusions on Cardiovascular Health (2024)[20] have strengthened the European political framework for a comprehensive approach to cardiovascular health one that goes beyond prevention to include **screening, early detection, equitable access to treatment, innovation and rehabilitation**.

> *"The Prague and Brussels Declarations show the evidence and the asks. The Council Conclusions give them political legitimacy."*
>
> **Kitti Almer, FH Europe Foundation**

Together with the Prague and Brussels Declarations, they demonstrate coherence between science, civil society, and institutional momentum.

This alignment strengthens the foundation for Europe's next steps, the **EU Cardiovascular Health Plan**, which will turn long-standing advocacy into coordinated national action ensuring that from prevention to rehabilitation, cardiovascular health is treated as a strategic European priority.

What Works: Research and Innovation

Innovation in cardiovascular prevention, including FH, is already producing real-world results. **Prof. Fausto Pinto**, **Prof. Mafalda Bourbon**, **Dr. Marius Geantă**, and **Dr. Andrie Panayiotou** illustrated three European projects, where FH Europe Foundation is in a consortium leading role (PERFECTO FH[13]) or a work package leader. The projects showcase how new communication models, data, technology and cross-border collaboration can bring early detection and personalised prevention as well as precision medicine to scale.

In his opening remarks, **Prof. Fausto Pinto** (Former President, European Society of Cardiology and World Heart Federation), underscored that innovation in inherited lipid disorders sits at the intersection of **science, clinical practice, advocacy and policy**. Drawing on his experience as a cardiologist and leader in global cardiovascular health, he stressed that meaningful policy change depends on strong advocacy and genuine co-creation between scientists and patients.

The panellists highlighted how the projects: **PERFECTO FH**[13], **FH-EARLY**[14] and **PerMed FH**[15] embody this collaborative model, bringing together patients, clinicians, and researchers to deliver **faster, more personalised, and accessible diagnosis and care**. These initiatives, although focused on FH, address the full spectrum of challenges in inherited lipid disorders, from genetics and early screening to personalised treatment pathways and prevention, while integrating **social and behavioural insights** to make innovation truly actionable.

Further on practical advances, including cutting-edge genetic and digital medicine platform to refine FH diagnosis, improve risk prediction, and enable truly personalised treatment plans developed as part of PerMed FH[15] and **novel diagnostic ChIP array, explainable AI tools** to support clinicians, and an **Expert Patient Panel** ensuring that lived experience drives research and implementation, as key focus of FH EARLY[14], were further explored by Prof Bourbon.

Dr. Marius Geantă (Romania) presented **PERFECTO FH**[13], an EU4Health–co-funded project that redefines cardiovascular prevention by addressing the **social and behavioural determinants of health** that drive 70% of outcomes but are often overlooked in biomedical models. Using **social science tools and generative AI**, the project maps population clusters and "personas" in **Romania and Cyprus** to design **personalised health communication and literacy campaigns**, ensuring prevention strategies resonate with real people. PERFECTO operates on three implementation levels—**national**, **community**, and **individual**—targeting both **East–West and urban–rural health inequities**. Dr. Geanta highlighted the project's synergies with the **4PCAN cancer prevention initiative**, which jointly tests and analyses cardiovascular risk, including **elevated Lp(a)**, demonstrating the power of integrating social, genetic, and behavioural data. Above all, he underlined the project's **commitment and sustainability**, with partners co-funding 40% of the budget, and urged the EU to maintain momentum through the forthcoming Cardiovascular Health Plan, where projects like PERFECTO FH and FH-EARLY can continue to scale impact and competitiveness[13,14].

Prof. Mafalda Bourbon (Portugal) explained that both **PerMed FH**[15] and **FH-EARLY**[14] focus on **improving diagnosis—the first and most critical step in prevention**. She described **PerMed FH** as a groundbreaking project that studies **genetic variants** to understand which mutations actually cause disease, using **functional assays** to determine how each affects the LDL receptor pathway. This will allow clinicians to tailor treatments based on individual protein function, ensuring **personalised prevention and precision medicine** that avoids overtreatment and improves outcomes. **FH-EARLY**[14], meanwhile, develops a **low-cost genetic ChIP array** that will make screening up to eight times cheaper than current sequencing, improving **cost-effectiveness and accessibility**. Alongside a **biomarker for personalised therapy and an AI-powered risk model** integrating multi-omics data, FH-EARLY creates practical, scalable tools that move Europe closer to **equitable, data-driven cardiovascular prevention**.

Dr. Andrie Panayiotou, representing a Cypriot partner in the **PERFECTO FH**[13] **consortium**, emphasised that **behavioural science and citizen-centred design** are crucial for making screening programmes socially acceptable and actionable. She explained how PERFECTO's **personalised communication models**, co-designed with patient organisations and tested in Cyprus and Romania, address cultural and social barriers to screening uptake by tailoring messages to diverse communities. This evidence-based, citizen-driven approach provides a **blueprint for Member States** to build effective national screening policies aligned with the **EU Cardiovascular Health Plan**. With **Cyprus preparing to assume the EU Council Presidency** and having just adopted its **National Strategy on Cardiovascular Disease**, Dr. Panayiotou highlighted the opportunity to leverage evidence and networks from projects like **PERFECTO FH, FH-EARLY, and PerMed FH** to advocate for **harmonised, equitable cardiovascular screening across Europe**—making prevention both a public health and a competitiveness priority[13-15].

All panellists agreed that these projects make innovation tangible, scalable, and impactful, and that with sustained EU support, they can help make **personalised prevention a defining feature of a competitive and compassionate Europe**.

Current research projects

PERFECTO FH[13]

(EU4Health – 60% co-funded) is a European Commission–supported project dedicated to advancing **paediatric screening for familial hypercholesterolaemia** through early detection and personalised prevention. As FH is the most common inherited cardiovascular risk factor worldwide, PERFECTO FH promotes the implementation of best practices for paediatric screening across EU Member States to reduce cardiovascular disease burden and health inequities. Central to the project is a **personalised, patient-driven communication model** that strengthens health literacy, fosters healthy living, and supports policy advocacy through active patient and citizen engagement.

FH-EARLY[14]

(Horizon Europe – 100% funded) is a multinational initiative uniting 15 partners to transform how FH is detected, stratified, and managed. The project develops **three co-created innovations:** a **rapid diagnostic ChIP array** to accelerate testing, a **biomarker assay** to support personalised risk stratification, and an **AI-powered health profiling tool** to guide precision care. Co-designed with patients, families, and clinicians, FH-EARLY ensures its solutions are ethical, accessible, and clinically meaningful. By combining digital innovation with **federated real-world data**, it aims to revolutionise early diagnosis and integrated care for FH across Europe.

PerMed FH[15]

(La Caixa Foundation – 100% funded) is building a **cutting-edge genetic and digital medicine platform** to refine FH diagnosis, improve risk prediction, and enable truly personalised treatment plans. By linking **clinical, molecular, and functional genomic data** through a **variant classification pipeline, drug optimisation platform, and interactive variant database**, PerMed FH empowers clinicians to deliver the right therapy to the right patient at the right time. The project represents a major step toward embedding precision medicine in routine clinical practice improving outcomes while ensuring treatments are cost-effective, safe, and sustainable.

Together, these projects exemplify Europe's capacity to **bridge research and real-world healthcare delivery**. By leveraging digital tools, interoperable data systems, and patient-driven innovation, they enable a new era of **personalised prevention**, one that tailors risk assessment, treatment, and follow-up to each individual's genetic and clinical profile. In this context, innovation is no longer optional; it demands implementation. By combining genomics, digital health, and real-world evidence, Europe can ensure that prevention is not only available but **targeted, proactive, and precise**.

Consensus and Momentum

The event reflected a historic convergence between science, patient advocacy, and political will. The hosts of the event, **Members of the Parliament, Romana Jerković (Croatia, S&D) and Tomislav Sokol (Croatia, EPP)** agreed that cardiovascular prevention must be treated as a shared European responsibility. During his intervention, Tomislav Sokol, MEP, urged for greater funding and better coordination at the EU level.

> ***"Health deserves its own line in the EU budget. Let's fund what we know works: screening and prevention."***
>
> **Tomislav Sokol, MEP**

For her part, Romana Jerković, MEP, highlighted the essential link between health and productivity and closed the event stressing the need for European policy-makers to address the burden of cardiovascular disease.

> ***"Let us leave this room not only inspired, but also determined to make cardiovascular health a true European priority and to prove that prevention is indeed the best, the smartest policy that we could have"***
>
> **Romana Jerković, MEP**

Health and competitiveness are inseparable. Preventing cardiovascular disease safeguards Europe's most valuable asset—its people. Healthy citizens sustain innovation, productivity and social cohesion, forming the foundation of Europe's economic strength.

Every euro invested in prevention yields returns not only through reduced healthcare costs but through decades of extended working life, lower disability rates, and greater intergenerational stability. The benefits of early detection and timely treatment accumulate over time, compounding across families, communities, and national economies.

By embedding cardiovascular health in its **long-term economic and social strategy**, Europe protects both present and future competitiveness, proving that prevention is not an expense but a lasting investment in prosperity.

Thus, the Commission's commitment to present a comprehensive **EU Cardiovascular Health Plan** by the end of 2025 marks a turning point. The event reinforced that this plan must integrate patient-centred prevention as a strategic investment for Europe's future. This message was conveyed directly to the EU Health Commissioner Olivér Várhelyi by FH Europe Foundation representatives just days before the event in the European Parliament.

Building on a decade of evidence and advocacy, FH Europe Foundation and partners outline three policy pathways to deliver cardiovascular prevention across Member States:

- Early detection & family-based prevention: paediatric FH screening, once-in-a-lifetime Lp(a) testing, and early genetic confirmation of rare forms.
- Equitable access & personalised medicine: fair access to testing and therapies, AI- and data-driven prevention via the European Health Data Space.
- Patient participation & system integration: involve patients in policy and research; embed prevention across life stages and health systems.

These pillars provide an actionable roadmap for the **EU Cardiovascular Health Plan**, ensuring prevention is delivered equitably, efficiently, and sustainably across Europe.

> ***"Investing in prevention is investing in Europe's next generation."***
>
> **Romana Jerković, MEP**

Meeting with EU Health Commissioner Olivér Várhelyi

Brussels, 18 September 2025—FH Europe Foundation representatives met with EU Commissioner Olivér Várhelyi to discuss priorities for the forthcoming EU Cardiovascular Health Plan. The exchange focused on Europe's silent challenge: the widespread underdiagnosis of inherited lipid disorders such as FH and Lp(a), as well as rarer forms like HoFH and FCS.

> ***"Around 90 million Europeans live with inherited lipid disorders—yet 98% of Lp(a) cases & 90% of familial hypercholesterolemia remain undiagnosed. Our EU CVD Action Plan will tackle this by boosting early detection and treatment for all living with cardiovascular conditions."***
>
> **Olivér Várhelyi, EU Commissioner for Health**

The meeting underscored strong political commitment to make early detection and equitable care core pillars of the upcoming **EU Cardiovascular Health Plan**.

Closing Reflections

Over the past decade, FH Europe Foundation and its partners have worked to turn patient stories into policy progress. The **Prague (2022)**[4,5] **and Brussels (2025)**[6,7] **Declarations** helped sustain visibility and unity among stakeholders, while the **Council Conclusions (2024)**[20]provided the political framework for EU-level action.

> ***"This is not the end of a decade of work; it is the beginning of implementation."***
>
> **Magdalena Daccord, FH Europe Foundation CEO**

As the European Commission prepares the **first EU Cardiovascular Health Plan**, the message from patients, clinicians and policy-makers is clear: **Europe can no longer afford to delay prevention since in the long run we will not be able to afford a health-repair-centric focus**.

The event concluded with a strong commitment from policy-makers for sustained collaboration and support to transform the great advocacy, scientific and innovation achievements into tangible, impactful actions.

> ***"Together, we can build a future where no child's life is cut short by a silent condition, where no family is shattered by preventable heart disease, and where every citizen, regardless of their country, has the chance to live a full and healthy life."***
>
> **Romana Jerković, MEP**

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Resources

FHEF European Parliament event 25.09.2029

Prague Declaration on FH Paediatric Screening 2022

Brussels International Declaration on Lp(a) Testing and Management 2025

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FH Europe Foundation

FH Europe Foundation represents the needs of people with familial hyperlipidaemias. Covering both the most common genetic and inherited conditions in the world and the rare conditions, the Foundation acts in the area of advocacy and patient support, drives public health policy improvements and collaborates progressively with leading European and the EU institutions—like the European Commission, the European Parliament and many other EU stakeholders.

FH Europe Foundation is the next stage in the evolution of FH Europe (fheurope.org), the European Network of FH patient organisations. It was initiated in 2015 by a group of leaders of HEART UK, FH Sweden, FH Portugal, FH Norway and FH Austria and supported by a volunteer Steering Group, with an administration centre set up at HEART UK. In 2016, FH Europe was established as a legal entity—a Charitable Incorporated Organisation (CIO) in England and Wales with five Trustees.

FH Europe transferred its legal base from a charity based in the UK to a Dutch-based European Foundation. It was registered in May 2022 and began trading in March 2023. This development reflects our aspiration to lead and engage effectively in EU projects to advance the interests of patients and citizens living with FH and related inherited hyperlipidaemias, and also be active in the wider European Cardiovascular Health Community.

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