FH Europe Foundation's Response to the Call for Evidence for the European Cardiovascular Health Plan

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#Prevent the Preventable

FH Europe Foundation

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Response to the Call for Evidence for the European Cardiovascular Health Plan

Introduction

Cardiovascular disease (CVD) remains the leading cause of death in the EU, with 5,000 lives lost each day and an estimated cost of €282 billion per year.[1] As As the European Commission prepares its first EU Cardiovascular Health Plan, FH Europe Foundation welcomes the opportunity to bring a patient- and citizen-led perspective. It centres on risk prediction, disease prevention, a shift towards health, equity, innovation and meaningful involvement of people with lived experience in the diagnosis and management of their conditions.[2]

FH Europe Foundation is a non-profit patients' organisation dedicated to supporting people living with inherited lipid disorders. As a network, it brings together 34 patient organisations, individual patients and affected families across wider Europe, Asia, Australia, the Middle East and the Americas. The Foundation helps raise awareness about familial lipid disorders, provides patient support and education, advocates on behalf of patients/people with lived experience and undiagnosed individuals, influences public health policy change, and leads and supports research.

Familial lipid disorders, including familial hypercholesterolaemia (FH) and elevated lipoprotein(a) [Lp(a)], are the most common inherited drivers of premature CVD, but remain largely invisible in public health strategies.[3] Together with rare and severe forms such as homozygous FH (HoFH) and familial chylomicronaemia syndrome (FCS), they are life-threatening if detection is delayed.[3,4] Yet, despite decades of global advocacy, including World Health Organization reports on FH from 1997 and 1998, detection rates remain extremely low across all 4 conditions.[5,6] Diagnosed early, these disorders can be effectively managed, and CVD can be prevented.

n estimated 90 million of EU inhabitants — one in every five — live with one or more familial lipid disorders that expose them to cardiovascular disease, risks that are both predictable and preventable.[7]

The forthcoming EU Cardiovascular Health Plan explicitly prioritises prevention, early detection/screening and better management, with a strong role for data, digital tools and AI under EU frameworks such as the European Health Data Space (EHDS). By embedding early detection of inherited lipid disorders in the forthcoming EU Cardiovascular Health Plan, Europe can turn genetic inevitability into a prevention success story. This aligns with the lessons learnt from Europe's Beating Cancer Plan, as well as the Council Conclusions on Cardiovascular Health (2024).[8,9]

FH Europe Foundation

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Understanding Familial Hypercholesterolaemia

Familial Hypercholesterolaemia (FH) – umbrella term for common and rare genetic high cholesterol

Familial hypercholesterolaemia: A genetic condition leading to lifelong high LDL-cholesterol and a markedly increased risk of premature coronary heart disease, running in families.[10]

Familial Hypercholesterolaemia (FH) literally means "running in the family too much cholesterol in the blood, from birth onwards." .

- Familial → it runs in the family (inherited from parents, passed to children).
- Hyper → very high
- Cholesterolaemia → cholesterol in the blood

FH is one of the most common inherited cardiovascular risk factors, yet one of the least recognised. It has a more common form, called heterozygous FH (HeFH), and a rarer, more severe form, called homozygous FH (HoFH). With HeFH (inherited from one parent), cholesterol levels more than double, and heart attacks can strike decades too early. With HoFH (inherited from both parents), cholesterol is extremely high, and heart attacks can occur already in childhood.[10]

"Think of it as being born with a ticking bomb in your arteries. From birth, bad cholesterol is dangerously high and rapidly builds up fatty deposits in the artery walls. FH is not lifestyle, it's DNA. But it can be detected with a simple test and treated effectively".

Heterozygous Familial Hypercholesterolemia (HeFH)

Prevalence: 1 person in 300 has HeFH – an estimated 2.5 million Europeans, including 500,000 children.[10]
Detection rate: It is estimated that only 10-20% of people with HeFH have been diagnosed, and fewer than 5% of children have been identified.[10,11] Most cases are still detected following a heart attack in secondary prevention.
Burden: 22-fold increased risk of premature coronary heart disease. Untreated HeFH increases the risk of early heart attacks. Around 50% of men with HeFH experience a heart attack by age 50, and 30% of women with HeFH by age 60. Avoidable hospitalisations, productivity losses, higher sick leave and early retirement often follow. Average age of the first heart attack in people with undiagnosed and untreated HeFH is 40.
Diagnosis: Universal paediatric screening (age 5-10) and family cascade and reverse cascade testing identify cases early and meet all Wilson-Jungner criteria.[12]

I was diagnosed with familial hypercholesterolaemia (FH) earlier this year. […] My diagnosis came early enough in life for me to be able to manage this disorder in a way that will allow me a regular, healthy life. My father wasn't as fortunate. He was only diagnosed with FH after his first heart attack had already happened. By then, irreversible damage had occurred. He went on to develop serious cardiovascular and atherosclerotic disease and, ultimately, passed away at 63 from complications that might have been prevented with early detection and proper care. Our story is not unique. […] The EU now has the opportunity to change the future for millions of families like mine.

Madalina Iamandei, 37, Romania

Prevention and care: Early statin therapy can normalise life expectancy from childhood. Access to available lipoid lowering therapies, combined lifestyle changes with smoking cassation, physical activity and diet.[10]
National experiences: Slovenia's national paediatric screening covers more than 91% of children. In 2023 Croatia kicked off a preschool lipid screening programme, Poland announced the plan to lunch it in 2025. For more data is generated as part of PERFECTO FH.[10]

Homozygous Familial Hypercholesterolemia (HoFH)

Prevalence: One of the rarest and most severe inherited cholesterol disorders, affects 1 in 250,000-360,000 people, about 10,000 citizens across Europe.[13]

Detection rate: fewer than 1 in 20 are diagnosed, and many are identified in their teenage years, when serious heart damage has already begun.[14]

Burden: Children with HoFH are born with extremely high cholesterol that damages arteries from the very start of life. Without specialist care, heart attacks can appear in early childhood, and fatal cases have been reported as young as 1.5 years of age. Most patients never reach safe cholesterol levels, facing a constant risk of early heart attacks, strokes, and premature death.[13,14]

Diagnosis: Very high cholesterol in blood, visible cholesterol deposits under the skin and around the eyes (xanthomas), family history of FH, high cholesterol, heart attacks and premature death in family. Diagnosis should be confirmed through genetic testing. Implementation of cascade and reverse cascade testing of family members is critical to diagnose other family members due to the genetic nature of the disorder.[13,14]

Prevention and care: When HoFH is identified early, children could access modern, life-saving treatments, including specialised medicines and treatments that dramatically reduce risk. Linking these children to expert lipid clinics and testing their families (reverse cascade screening) is critical to protect lives across generations.[13,14]

Understanding Elevated Lp(a)

Description: Elevated Lp(a) is an inherited, independent and causal risk factor for atherosclerotic cardiovascular disease (ASCVD) including coronary artery disease, stroke, peripheral arterial disease and aortic valve stenosis. Around 90% of levels are genetically determined and remain stable from childhood, unaffected by lifestyle. Levels may vary slightly in women later in life due to hormonal changes.[15]

Prevalence: About 1 in 5 people, nearly 20% of Europeans, have elevated Lp(a) above the high-risk threshold of 50 mg/dL.[15]

Detection rate: Only 1-2% of citizens are tested, despite the availability of simple, low-cost assays.[16,17]

In terms of testing, we have guidelines and consensus available which clearly state that Lp(a) should be measured in every person as early as possible, at least once in a lifetime. But only 1 to 2% of the population till now got an Lp(a) measurement.

Prof. Florian Kronenberg

Burden: Elevated Lp(a) can raise the risk of heart attack and stroke by 50–200% and is estimated to be six times more atherogenic than LDL cholesterol on a particle-for-particle basis.[15] Each year, elevated Lp(a) is responsible for thousands of preventable premature cardiovascular events, including early heart attacks, strokes, and cases of aortic valve stenosis. Importantly, Lp(a) should always be evaluated in the context of overall cardiovascular risk, taking into account other factors such as high cholesterol, diabetes, hypertension, and obesity, etc.[17]

Diagnosis: A once-in-a-lifetime blood test is sufficient to identify elevated Lp(a), as the levels stabilise at the age of 5. Implementation of cascade and reversed testing of family members critical to diagnose other family members due to the genetic nature of the disorder.[17] However, since the condition is so frequent, a systematic testing of the general population is recommended by guidelines.

Prevention and care: While specific Lp(a)-lowering treatments are still in development, risk can be reduced through intensive management of other cardiovascular risk factors: lowering LDL cholesterol as much as possible, controlling blood pressure, smoking cessation, maintaining healthy weight and diet, and increasing physical activity. Identifying elevated Lp(a) early enables clinicians to reclassify risk, adjust treatment plans, and protect families across generations.[18]

I was a healthy father of three. I was fit, did a lot of sport and never smoked. Only to experience a heart attack at the age of 39. "Bad luck"- I was told. It took 6 very long years and two heart attacks, until diagnosis and the root cause of my heart/artery issues was identified. As elevated levels of Lp(a) is genetic, my family was also tested and two of my daughters unfortunately inherited this disorder. This was difficult to accept at first, but currently I am confident that they will be able to live a healthy life (now that they are aware).

Marc Rijken, 50, the Netherlands

Understanding Familial Chylomicronemia Syndrome (FCS)

Description: FCS is an ultra-rare inherited lipid disorder causing extremely high triglycerides and recurrent, sometimes life-threatening pancreatitis. It requires lifelong management and specialist care.[18]

Prevalence: The best available estimates suggest that FCS affects approximately 1 in 1,000,000 people, with higher prevalence observed in certain founder populations.[18]

Detection rate: Due to the rarity of the disease, many patients are estimated to be undiagnosed or misdiagnosed for years.[18] More research would be needed to better assess the misdiagnosis rate.

Burden: FCS causes severe abdominal pain, recurrent hospital admissions for acute pancreatitis, and major psychosocial impacts. Patients often face restrictive, extremely low-fat diets, anxiety, isolation, and limitations in education and employment. Patient-reported studies document profound quality-of-life loss and disruption to work.[18,19]

Note: Acute pancreatitis admissions are resource-intensive across Europe, urepresenting a substantial and avoidable burden on healthcare systems. Timely diagnosis is therefore critical to reduce both costs and preventable patient suffering..[18]

Diagnosis: Early genetic confirmation - crucial for distinguishing FCS from multifactorial hypertriglyceridaemia - shortens the diagnostic odyssey and enables tailored care pathways. Testing should be initiated whenever there is strong phenotypic suspicion.[18]

Prevention and care: Management requires a combination of a very-low-fat diet, regular specialist follow-up, and, where appropriate, innovative triglyceride-lowering therapies. Ensuring equitable access to both treatments and expert centres is key to reducing pancreatitis episodes, hospitalisations, and the broader societal costs.[18,20,21]

jessica-rockowitz

Evidence Generation

FH Europe Foundation's response draws on several years of active involvement and advocacy as a Partner of the European Alliance for Cardiovascular Health (EACH). It complements the recently published roadmap A European Cardiovascular Health Plan: The Roadmap. The evidence used in the submission builds on the successful recognition of FH Paediatric Screening as a Best Practice on the EU Public Health Portal, as well as three high-level events under the Slovenian, Czech and Polish EU Presidencies of the Council. Those events generated further evidence which has been published, including two consensus-based declarations – the Prague Declaration on FH and the Brussels International Declaration on Lp(a).[17,24]

Furthermore, three groundbreaking research projects, two of which have been EU funded, provide further findings to support this submission. These include PERFECTO FH (EU4Health), FH EARLY (Horizon Europe) and PerMed FH (Fundación "La Caixa").[25,26]

In preparing this submission, the FH Europe Foundation consulted its network of patients, advocates and scientific experts via dedicated community calls and structured feedback loops.

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Evidence and Transferability of Lessons from EU funded projects

PERFECTO and FH-EARLY to Cardiovascular Health (CVH) Plan

The table below highlights the main evidence generated by the PERFECTO and FH-EARLY projects, which are already focused on cardiovascular prevention and familial hypercholesterolaemia (FH). Their findings provide direct policy lessons for early detection, cascade screening, patient engagement, and the responsible use of digital and AI-enabled tools. These insights can guide the design of the EU CVH Plan to ensure it is evidence-based, citizen-centred, and future-ready.

	Key Lessons	Transferable recommendations
perfecto Preventing the Preventable	Public awareness of lifestyle risks is relatively high, but knowledge of genetic risks (like familial hypercholesterolaemia – FH) remains very low (22–28% awareness). Despite this, citizens show strong willingness (>70%) to undergo cholesterol/genetic testing if recommended by trusted professionals. The Personalised Communication Model (PCM) – micro/meso/macro – improves engagement, trust, and follow-up.	• Adopt the PCM at EU/national/ regional level for cholesterol testing and FH screening. • Operationalise cascade testing (paediatric + family-based) across Member States. • Make trusted professional recommendation the trigger for • testing. • Prioritise disadvantaged groups (rural, low-income, women).
FH EARLY	Innovative tools for early FH detection (chip array, biomarker assay, XAI-driven risk profiling) are promising but trust in AI is low. Patients only accept them when explained by trusted clinicians and supported with plain-language, visual aids. Co-creation with patients and families builds legitimacy and ensures usability.	• Set EU standards for “explainability-first” AI-enabled CVH tools. • Requireclinician-mediated introduction and plain-language / visual explanations. • Establish EU-wide co-creation protocols with patients and families for digital/AI CVH tools. • Track KPIs on trust, comprehension, and uptake of such innovations.

PERFECTO (https://perfecto-fh.eu) - focused on childhood screening programs for inherited high cholesterol (paediatric familial hypercholesterolaemia), which runs in families. screening in Europe. PERFECTO's primary goal is to promote the use of FH Paediatric Screening throughout Europe. With a special emphasis on countries with the greatest rates of cardiovascular disease and low levels of public knowledge of FH, the project seeks to establish a supportive and enabling environment. PERFECTO aims to present concrete proof of the beneficial effects that preventative measures, such as FH Paediatric Screening, have on individuals and their families, on population health, and healthcare systems.

FH-EARLY (https://fh-early.eu) - focused on improving early detection and management of familial hypercholesterolaemia (FH), one of the most common inherited metabolic disorders. The project aims to deliver a chip array for earlier, cheaper diagnosis, a signature biomarker assay for risk stratification, and a XAI driven integrative precision health profiling tool. The project uses co-creation methods
PerMed FH

Prevention (e.g. by addressing unhealthy behaviours to reduce the risk factors)

PERFECTO

Through surveys, consultations, and focus groups conducted in Romania and Cyprus, the project generated new evidence on public perceptions, behaviours, and barriers to early detection. Findings revealed that while awareness of lifestyle risk factors is high, knowledge of genetic risks such as FH remains strikingly low (only 22% of Romanians and 28% of Cypriots had ever heard of FH). At the same time, citizen willingness is strong: over 70% of respondents said they would participate in cholesterol or genetic testing and recommend it for their children and relatives. To address these gaps, PERFECTO developed a Personalised Communication Model (PCM), a scalable framework that tailors messages to different audiences and contexts. The model uses data-driven personas and clusters to adapt communication at three levels: micro - engaging families and close networks; meso – empowering family doctors, teachers, and community leaders; macro - leveraging media, digital platforms, and national campaigns. This layered approach responds to inequalities revealed by the project: rural and socioeconomically disadvantaged groups are less engaged with prevention, while women often lead health decisions but carry disproportionate responsibility. By adapting strategies to these realities, the PCM helps build trust, improve follow-up after testing, and reduce health inequalities.

For CVH: Adopt a layered, personalised prevention strategy that operationalises communication and engagement across three levels to close gaps in awareness and uptake of cardiovascular health (CVH) measures.
Building on the Personalised Communication Model (PCM), interventions could focus on: the micro level (family and close networks) to promote testing through trust-based dialogues within households and close networks (accounting, as well, for women's important role in health-decision making); meso (community and frontline
professionals) - equip family doctors, teachers, and community leaders with tailored tools and culturally relevant narratives to increase early detection, particularly in rural and socioeconomically disadvantaged areas where engagement is lowest; macro (societal and system-wide) - implement national and regional campaigns that combine traditional media, digital platforms, and public institutions to normalise prevention behaviours, destigmatise genetic testing, and integrate citizen-driven insights into health policy.

Early detection and screening (e.g. through an EU protocol on health checks or EU guidance on using digital tools for personalised treatment and remote monitoring)

PERFECTO shows that citizens are ready to act on early detection if systems provide access, guidance, and trusted communication. Family doctors and community influencers have an important role in building trust and
ensuring follow-up.

For CVH: Establishing EU-level guidance on paediatric cholesterol testing and cascade screening would ensure systematic early detection across EU Member States. Embedding this into the EU Cardiovascular Health Plan would prevent thousands of premature CVD deaths, reduce inequalities, and establish screening as a model for personalised prevention across Europe. The CVH plan should harness the European Health Data Space to enable predictive, personalized cardiovascular care.

Innovative, patient-centred and personalised solutions to help prevent, detect as early as possible, and treat

FH_EARLY

As part of the project, three innovative tools - a chip array for earlier, cheaper diagnosis, a signature biomarker assay for risk stratification, and a XAI driven integrative precision health profiling tool - will be developed. The chip array is intended to be a comprehensive, yet cheap solution that allows to identify monogenic, polygenic, and other causes of inherited dyslipidaemia, and is designed for a quick interpretation in routine care. The signature biomarker assay is a cellular readout distilled into 28 core features capturing lipid uptake/ storage in lymphocytes and monocytes – used for stratifying therapy and assessing risk. The XAI tool intends to fuse multi-modal data (clinical, genomics, imaging, biomarkers) to predict risk and support care plans. As part of the project, an Involvement Protocol for FH Patients and Families was developed, that embeds ethical, patient-centred co-creation into FH EARLY, detailing how patients and families are consulted in relation to the tools to be developed. Up to now, a concept pre-test of the planned instruments was conducted with FH patients. It revealed low baseline trust in AI based tools unless they are recommended and discussed by a trusted healthcare professional and highlighted the need for plain-language descriptions supported by visuals where possible.

For CVH: Adopt a mediated, explainability-first approach for AI-enabled CVH tools. We recommend requiring introduction via trusted healthcare professionals, providing standard plain-language descriptions and visual aids codesigned with patients, and - if possible - tracking KPIs on trust and comprehension.

Detecting Risk Before Disease: Screening as the Gateway to Cardiovascular Prevention

Systematic and early screening for inherited cardiovascular risk factors, including familial hypercholesterolaemia (FH) and elevated lipoprotein(a) [Lp(a)], is essential to shift from a reactive model of care to one that prioritises the preservation of cardiovascular health (CVH).

Rather than waiting for the first heart attack or stroke, early detection reframes people not as patients defined by disease, but as individuals with manageable risk factors who can benefit from timely, preventive care. In addition, adopting family-based approaches, creates cost savings as one diagnosis triggers cascade or reverse-cascade testing to protect whole families across generations

This approach allows families and health systems to act decades ahead of irreversible damage, turning a reactive model into one that promotes resilience, longevity and improved quality of life.

I was diagnosed as a child at the age of 6, as part of the routine family cascade screening in the Netherlands. My dad had a family history of high cholesterols and CVD, and then we heard of FH. To everyone's surprise I didn't have FH, but elevated Lp(a). This triggered the reverse cascade screening. And this is how my mom was diagnosed with elevated Lp(a). The family-based screening has unravelled a complex genetic mix in our family and at the same time helped identify everyone at risk early enough to prevent any tragedy

Aeden Kaal, 19. The Netherlands.

Cost-Effectiveness of Screening & Testing

CVD prevention strategies that identify high-risk individuals early, particularly those with FH or elevated Lp(a), can avert premature events and long-term treatment costs. Economic evaluations consistently show that well-designed screening programmes for these conditions deliver good value for money in high-income settings, especially when paired with effective treatment pathways and cascade testing of relatives. Evidence from studies on FH and elevated Lp(a) demonstrates that early screening and testing are not only cost-effective, but also cost-saving, delivering measurable benefits for both healthcare systems and society as a whole.

Familial Hypercholesterolaemia (FH)

1) Cascade screening from an index case (adults & children)

Finding: Cascade screening of first- and second-degree relatives of an index FH case is consistently highly cost-saving (often the most efficient strategy) because of the high prevalence among relatives and the significant early risk reduction achieved with timely treatment.
Drivers of value:

- High detection yield in families (due to autosomal dominant inheritance).
- Low marginal cost of each additional relative tested.
- Substantial lifetime QALY (quality-adjusted life year) gains from earlier lipid-lowering therapy.

2) Universal or opportunistic child screening with reflex cascade to families

Finding: Universal child screening (typically at a single childhood touchpoint) can be cost-effective or even cost-saving when it triggers cascade testing upstream in families. Opportunistic screening (e.g., at vaccination visits) can approximate this value if coverage is high.
Drivers of value:

- Early LDL-C reduction prevents decades of exposure.
- Each child identified unlocks multiple relatives via cascade.
- One-time (or infrequent) screening captures many undiagnosed cases early.

3) Adult population or opportunistic screening

Finding: Adult-focused strategies can be cost-effective when integrated into existing care touchpoints (primary care, CVD risk assessment), particularly if positive result automatically trigger cascade testing. In addition, such programmes also identify adults with elevated LDL-C from causes other than FH, ensuring these individuals receive appropriate attention and treatment to reduce their risk of CVD
Drivers of value:

- Moderate detection rates at the individual level.
- Significant additional value generated through cascade testing of relatives.

Country example

Evidence from the Netherlands demonstrates both health and economic benefits of early FH detection. A 20-year national cascade screening programme identified over 26,000 FH carriers, including 5,600 children, by systematically tracing families from index cases. Health economic modelling of paediatric screening showed that early detection and statin initiation at age 10 yields an average gain of 2.53 quality-adjusted life years (QALYs) per person compared to late diagnosis, at an incremental cost-effectiveness ratio of only €9,220 per QALY—well below the Dutch threshold of €20,000. From a broader societal perspective, the programme was cost-saving, with **every €1 euro invested generating an estimated €8.37 return on investment through reduced premature heart attacks, hospitalisations, and productivity losses**. These findings confirm that systematic paediatric FH screening is not only life-saving but also delivers excellent value for European health systems.[26]

Elevated Lipoprotein(a) [Lp(a)]

Once in a person's lifetime testing in adults

Finding: In high-income health systems, one-time Lp(a) testing in adulthood (e.g., at first comprehensive CVD risk assessment) is generally cost-effective as a risk-refinement tool — especially for individuals at borderline to intermediate 10-year risk or with a family/personal history suggestive of elevated Lp(a).

Drivers of value:

- Single test, lifelong signal: Lp(a) is genetically determined and stable; a once-only test informs lifelong risk management.
- Risk reclassification: Identifies a subset at substantially higher risk, supporting intensified prevention (LDL-C-lowering targets, aspirin in select secondary prevention contexts per guidelines, earlier imaging, etc.).
- Downstream efficiency: Focuses resources (clinics, imaging, pharmacotherapy) on those with the greatest expected benefit.

Not only we are going to save lives in terms of cardiovascular disease, but we are going to improve people's life, save costs from a health-care perspective, but also from a societal perspective.

Prof. Zanfina Adem

Regional example

A recent multinational health-economic analysis in 11 high-income countries, including France, Germany, Italy, the Netherlands, Spain, Poland, Austria and the UK, demonstrated that universal Lp(a) testing in primary prevention is cost saving (more effective and less costly). **Health-economic modelling demonstrated that testing would prevent 60 first heart attacks, 13 strokes and 26 premature deaths per 10,000 individuals, and would lower healthcare costs between ≈75-450€ per person in the explored EU countries**.[28] Reclassification of almost 20% of adults into higher-risk categories leads to earlier initiation of intensive LDL-C lowering and better blood pressure control, preventing heart attacks and strokes and avoiding costly revascularisations. From a societal perspective, incorporating productivity losses and premature mortality, Lp(a) testing was intervention was cost-saving from both the healthcare and societal perspectives as supported by the analysis across European health systems.

Policy Momentum

- **Council Conclusions on Cardiovascular Health** (2024) recognised inherited lipid disorders like FH and elevated Lp(a) as CVD risk factors and the need to implement early screening for better detection and prevention.[9]
- **Prague Declaration on FH** (2020) and **Brussels International Declaration on Lp(a)** (2025) both call for systematic screening and inclusion in EU/National health plans.[16,23]

Prague Declaration calls for:

1. Political leadership and commitment to make FH paediatric screening a reality
2. Investment and a policy framework for raising awareness of FH amongst medical practitioners and the public, to build trust and responsiveness
3. Comprehensive early detection, screening, diagnosis and life course care programmes in every country
4. Specific actions to address the barriers to successful large-scale uptake of screening programmes and subsequent treatment
5. Targeted R&D to address knowledge gaps
6. Building the capacity of health professionals and empowering patients on how to best support individuals and families with FH
7. Commitment to shared learning and monitoring through exchange and comparisons beyond borders in- and outside the EU

Brussels Declaration calls for:

1. Lp(a) in Cardiovascular Health Plans: Integrate elevated Lp(a) Testing and Management into Global, European and National Cardiovascular Health Plans
2. Investment, workable policy and programmes: Ensure appropriate investment, policy and programmes in Lp(a) Testing and Management based on the recent study demonstrating the significant overall cost saving to health systems across the globe
3. Political Leadership and Commitment: Advocate for political commitment to mandate systematic Lp(a) testing at least once during a person's lifetime, ideally at an early age, with full reimbursement
4. Global Cardiovascular Risk Assessment: Ensure testing is undertaken in the context of global cardiovascular risk assessment, and to develop personalised cardiovascular health roadmaps as needed, without fear of discrimination
5. Raising Awareness: Drive investment in public and healthcare professional education to increase awareness of Lp(a) and its impact on cardiovascular health

Transformational digital tools and ethical Artificial Intelligence will facilitate the implementation of systematic testing for, and effective personalised management of elevated Lp(a). Shared learning beyond borders, impact assessment, monitoring and evaluation will chart progress on an annual basis.

The ball is now in the court of us, politicians. The best thing that we could do is to ensure that the declaration is incorporated and that the Lp(a)is addressed in the upcoming European Cardiovascular Disease Plan.

MEP Romana Jerkovic
(about the Brussels Declaration)

Our efforts on prevention need to start at an early age to support healthy lifestyles. Early screening and detection of those at risk for developing cardiovascular diseases is also essential. The plan for European cardiovascular health will build on the EU's Healthier Together initiative on non-communicable diseases. Ongoing projects under this initiative include PERFECTO, which addresses inherited high cholesterol, one of the risk factors that could lead to an increased risk of cardiovascular diseases.

Commissioner Olivér Várhelyi

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Key Policy Considerations

Familial hypercholesterolaemia (FH) and elevated lipoprotein(a) [Lp(a)] are the most common inherited lipid conditions in Europe. They are major drivers of premature heart attacks, strokes and other cardiovascular diseases, yet remain largely invisible to citizens and in public health strategies. Around one in 300 people live with FH and one in five with high Lp(a). These conditions cut lives short and place a heavy burden on families and societies. Most people affected are not diagnosed and therefore do not benefit from efficient treatment and care. Rare and severe inherited conditions, such as homozygous FH (HoFH) and familial chylomicronaemia syndrome (FCS), can be life-threatening if detection is delayed, yet no screening programmes exist. The Council Conclusions on Cardiovascular Health (2024) recognised lipid disorders, including high cholesterol and inherited conditions, as key priorities for action.[9]

The EU Cardiovascular Health Plan is a unique opportunity to act by putting prevention at the centre. Unlike lifestyle-related risks, FH and Lp(a) are genetic, unavoidable but manageable once identified. Simple, affordable blood tests can detect them early in life, allowing families and doctors to prevent heart attack risk for decades. Early action means fewer hospitalisations, heart attacks and years lost to illness. For FH, all forms of testing are more cost-effective than none. For Lp(a), a once-in-a-lifetime test can reclassify risk and guide tailored treatment.

Research shows that integrating Lp(a) testing into prevention programmes is clinically effective and cost-saving. For every 10,000 people tested, up to 60 heart attacks, 13 strokes and 26 premature deaths can be avoided. By identifying high-risk individuals earlier, health systems can reduce the need for costly acute care, improve quality of life and prevent productivity losses due to sick leave or early retirement. Each €20-40 test saves €174 per patient in the UK, $85 in Australia and up to $1,167 in the USA. With increasing testing rates, the costs of the tests are expected to decrease substantially over the coming years. Each missed opportunity represents decades of prevention lost. Beyond healthcare budgets, nationwide paediatric FH screening and systematic Lp(a) testing strengthen Europe's competitiveness by protecting its workforce, making it both a health and an economic imperative.

Cardiovascular health strategies must also address inequities from missed early diagnosis. Recognising the inherited and familial nature of these conditions allows one diagnosis to protect whole families across generations. Women are underdiagnosed, disadvantaged groups face higher barriers and many children remain undetected, despite reliable tests. A strong focus on equity is essential so that everyone, regardless of gender, background or socio-economic status, has equal access to early detection and care.

Innovation can drive this vision. Digital tools, AI and personalised prevention can predict risk more accurately and enable tailored care. Linking genetic and clinical data through the European Health Data Space can shift prevention from reactive to predictive. AI can identify hidden patterns, flag high-risk individuals earlier, and support effective care, while patient-centred approaches co-designed with those living with FH and elevated Lp(a) raise awareness, improve adherence and build trust. Systematically identifying and managing FH and high Lp(a) not only reduces healthcare costs and avoidable hospitalisations, but also delivers wider benefits for productivity, education, competitiveness and social equity.

FH Europe Foundation calls on the European Commission to ensure that FH and Lp(a) testing and management are embedded in the EU Cardiovascular Health Plan. The EU can add value by supporting Member States to scale up effective screening and prevention measures, while respecting national competences. By aligning with the commitments of the Prague Declaration on FH and the Brussels Declaration on Lp(a), the Plan can provide a unifying framework that strengthens both European cooperation and national action.

Recommendations: Inherited Lipid Disorders & CVD prevention

1. Political leadership & commitment - Embed familial lipid disorders into the EU Cardiovascular Health Plan

- Formally recognise FH and elevated Lp(a) as serious, common, and manageable CVD risk factors alongside hypertension, diabetes and smoking.
- Align with the Council Conclusions on Cardiovascular Health (2024) and Prague Declaration on FH paediatric screening (2022) and Brussels International Declarations on Lp(a) testing and management (2025).

2. Make early screening and detection a cornerstone of prevention

- FH: Implement universal FH screening (at age 5–10), combined with cascade and reverse-cascade testing in families. Leverage existing screening opportunities (vaccination, pre- and school check-ups, etc) in line with the EU Best Practice on FH Paediatric Screening.
- Lp(a): Introduce a once-in-a-lifetime test, ideally in early in life (childhood/adolescence), with full reimbursement and linked to global cardiovascular risk assessment.
- Rare disorders (HoFH, FCS): Ensure early genetic confirmation through national screening protocols for rare diseases, like inclusion in newborn screening.
- Adopt family-based approaches: one diagnosis must trigger cascade or reverse-cascade testing to protect whole families across generations.

3. Ensure equity in access to testing and personalised management pathways

- Ensure access to testing regardless of gender, background or income, addressing the persistent underdiagnosis in women, children and disadvantaged groups.
- Ensure equitable access to lipid-lowering therapies, including novel therapies and specialised treatments for severe lipid disorders, across Europe, guided by the principles of personalised prevention.
- Ensure that individuals diagnosed with inherited lipid disorders are not placed at a disadvantage or treated unfairly in access to financial services, insurance, employment, or other areas of social participation. Safeguards should be in place to prevent discrimination based on genetic or medical status.

4. Include the voice of people with lived experience

- Include the voice of people with lived experience, in line with the WHA Resolution on Social Participation.[2]
- Recognise lived experience and quality of life as central to cardiovascular health strategies.

5. Support Member States with EU-level action

- Provide shared EU guidance, protocols, and pooled resources to scale up FH and Lp(a) screening. like the EU Best Practices.
- Integrate systematic screening into early EU health checks and national prevention pathways.

6. Strengthen awareness, professional capacity, and innovation

- Link genetic and clinical data through the European Health Data Space for predictive prevention and personalised management.
- Apply AI tools to identify undiagnosed cases and develop personalised cardiovascular health roadmaps.
- Invest in public and professional education to raise awareness of inherited lipid disorders, FH and elevated Lp(a).
- Equip healthcare professionals with training and digital tools, link registries and genetic data via the European Health Data Space, and foster research into new diagnostics and therapies.

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