

## **FH Awareness Day Press Release**

*Prevent the Preventable: Understanding the Genetic Risks Behind High Cholesterol for Better Cardiovascular Health Outcomes.*

### **FH Europe Foundation highlights the genetic cause of high cholesterol on FH Awareness Day, September 24, 2024**

**Amsterdam, The Netherlands, September 24, 2024** — As we mark FH Awareness Day on September 24, FH Europe Foundation calls attention to the critical need for increased awareness, early diagnosis, and appropriate management of Familial Hypercholesterolaemia (FH), a genetic disorder that significantly raises the risk of cardiovascular disease from an early age. This year, the Foundation is also proud to spotlight its leadership in two cutting-edge projects: PERFECTO and PerMed FH, both of which emphasise the importance of early screening, of personalised prevention and precision medicine in tackling the burden of FH detection and management.

### **Understanding FH: The Difference Between High Cholesterol and Genetically High Cholesterol**

High cholesterol is a significant public health challenge in Europe, contributing heavily to the burden of cardiovascular diseases (CVDs), which remain the leading cause of death across the continent. In 2020, cardiovascular diseases were responsible for approximately 32.7% of all deaths in the European Union (EU), which equates to about 1.7 million deaths. In 2021 CVD cost the EU economy EUR 282 billion, 100 billion more than the entire EU budget. This makes CVDs more deadly than any other disease category, including cancer (22.5% in 2020). And undoubtedly very costly.

High cholesterol is a key risk factor for ischemic heart disease\* and stroke, which are the most prevalent types of cardiovascular diseases in Europe. It is estimated that around one-third of ischemic heart disease cases globally are attributable to high cholesterol levels. This condition leads to significant healthcare costs and loss of life years due to disability and premature death. Across Europe, there are stark regional differences in the impact of high cholesterol on cardiovascular health. For instance, Eastern European countries generally report higher mortality rates from ischemic heart diseases related to cholesterol than Western European nations. This discrepancy is partly due to differences in diet, healthcare access, the social determinants of health, and public health initiatives. Efforts to reduce the burden of high cholesterol and associated CVDs in Europe include public health campaigns promoting healthier lifestyles, improved management of cholesterol through medication, and policies aimed at reducing trans fats and promoting heart-healthy diets.

High cholesterol is generally associated with unhealthy lifestyle factors such as poor diet, lack of exercise and tobacco use. However, Familial Hypercholesterolaemia (FH) is a genetic condition that leads to extremely high levels of low-density lipoprotein (LDL) cholesterol from birth. This condition is not caused by lifestyle but by inherited genetic mutations, in one of the following genes: LDLR gene, APOB gene, and PCSK9 gene. While many people develop high cholesterol over time due to lifestyle choices, those with FH are at a significantly higher risk of early heart attacks and other heart health complications, even if they maintain a healthy lifestyle. And as it is a familial disorder, it affects blood relatives from one generation to the next.

FH has two forms. The heterozygous FH (HeFH) is the most common inherited metabolic disorder, affecting approximately 1 in 300 people, which makes over 30 million people globally. In Europe alone, around 2.5 million individuals, including 500,000 children, live with FH, yet only an estimated 10% have been diagnosed and treated. There is also the more rare and severe form, called homozygous FH (HoFH), which occurs when a child inherits mutated genes from both parents. Without

early detection and intervention, individuals with HoFH face a risk of heart attacks, strokes, and other serious cardiovascular conditions already in the first decade of their lives.

Without the correct diagnosis, individuals with genetic high cholesterol are often undertreated, while the opportunity to screen their blood relatives is unfortunately missed.

### **PERFECTO: Preventing Cardiovascular Disease Through Paediatric Screening**

The PERFECTO project, recently launched and co-funded by the European Union, represents a groundbreaking initiative in personalised prevention. Focused on FH paediatric screening, PERFECTO aims to create robust evidence supporting the implementation of early screening across Europe. Early identification of children and their relatives with familial high cholesterol, followed by appropriate interventions, can dramatically reduce the risk of cardiovascular disease later in life. The project aligns closely with the EU Cardiovascular Health Plan, which emphasises the importance of early detection and preventive healthcare.

### **PerMed FH: Tailoring Treatment Through Precision Medicine**

Another critical project, PerMed FH, launched in January 2024, focuses on the application of precision medicine in diagnosing and managing FH. This project, coordinated by leading European research institutions, aims to improve the understanding of the genetic variations associated with FH and develop personalised treatment plans based on an individual's specific genetic makeup. By tailoring treatments to the genetic profile of each patient, PerMed FH seeks to enhance treatment efficacy, improve patient outcomes, and reduce the incidence of cardiovascular events because of high cholesterol.

### **Integrating Efforts on the National, European and global level**

This promises to be not just a day, but in some cases a week, of powerful national events covering awareness, education, healthy lifestyles and opportunistic screening for FH Europe Foundation's Network of patient organisations. Members from Austria, Czechia, Croatia, Ireland, Greece, Hungary, even Singapore, among many have activities planned! In the course of preparation for the big day, open community calls attracted attention of friends and partners as well as new groups and individual medical experts from Moldova, Canada, Greece, Germany, the Middle East, and more.

The FH Awareness Day happens against the backdrop of intensified efforts by the European Alliance for Cardiovascular Health (EACH) to establish a European Cardiovascular Health Plan. FH Europe Foundation together with the Network and Patient Ambassadors, has provided crucial contributions to the broader EU Cardiovascular Health Plan proposal over the years. The proposal seeks to reduce the burden of cardiovascular disease across the continent, by focusing on five pillars, which incorporate widespread screening, early diagnosis, personalised treatment, and quality of life.

Following the FH Awareness Day, the world will be celebrating the World Heart Day, September 29<sup>th</sup>, with the focus on a global petition led by the World Heart Federation (WFH) demanding to prioritise cardiovascular health policies. FHEF has been delighted to sign it and invites everyone to take action which will help save lives.

### **Call to Action: Understand the Difference, Act on Early Detection**

As we mark FH Awareness Day, Magdalena Daccord, FH Europe Foundation's CEO highlighted "*It is crucial for everyone—policymakers, healthcare providers, and the public - to recognise the difference between lifestyle-induced high cholesterol and the genetic risk posed by FH. We urge individuals to*

*learn more about FH, a condition that affects millions across Europe but remains underdiagnosed. Families with FH should not endure more heart attacks.” Prof. Albert Wiegman from the Netherlands added “Early screening and detection have been proven to be both cost effective and possible to implement.” Dr Marius Geanta, FH Europe Foundations Innovation Committee Chair concluded “Combined with personalised prevention and precision medicine, they are essential tools in preventing the preventable, allowing individuals to live healthier. However, these efforts require robust policies that prioritise these approaches within the broader healthcare system.” The urgency to act is clear.*

Visit FH Europe Foundation's website to learn more about FH and how you can support efforts to ensure that everyone at risk receives the care they need.

Contact: FH Europe Foundation

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**About FH Europe Foundation:**

FH Europe Foundation is a leading organisation dedicated to raising awareness, improving diagnosis, and supporting individuals affected by Familial Hypercholesterolemia across Europe. The Foundation collaborates with patients, healthcare providers, researchers, and policymakers to advocate for better cardiovascular health outcomes.

\* Ischemic means that an organ (e.g., the heart) is not getting enough blood and oxygen. Ischemic heart disease, also called coronary heart disease (CHD) or coronary artery disease, is the term given to heart problems caused by narrowed heart (coronary) arteries that supply blood to the heart muscle.