

Addressing remaining gaps in early detection of inherited lipid disorders: insights from the EU PERFECTO project

Brussels, April 2026 — Cardiovascular diseases continue to claim more lives than any other health condition in Europe. In response, policymakers, clinicians, patient organisations and researchers will gather in Brussels this April (27-28) for the closing event of the **EU co-funded PERFECTO project** “*Preventing the Preventable—Familial Hypercholesterolaemia Paediatric Screening for Cardiovascular Health.*” The two-day event, held under the auspices of the Cyprus Presidency of the Council of the European Union 2026, will mark a decisive step toward scaling up screening for inherited lipid disorders, a largely underdiagnosed group of conditions that significantly increase the risk of premature cardiovascular disease.

The event will come at a pivotal moment for European health policy. With the launch of the EU Safe Hearts Plan—where PERFECTO is already referenced as a relevant initiative—there is strong momentum to strengthen prevention and early detection strategies across Member States. PERFECTO partners will present supporting tools that can help translate this ambition into practice.

Inherited lipid disorders—including familial hypercholesterolaemia (FH), homozygous FH (HoFH), elevated lipoprotein(a), and familial chylomicronaemia syndrome (FCS)—represent a major yet often invisible driver of cardiovascular disease. FH alone affects an estimated **2 million adults** and **500,000 children across Europe**, yet the majority remain undiagnosed¹.

Co-funded under the EU4Health programme, PERFECTO was developed to advance the uptake of systematic screening for inherited lipid disorders across Europe, with a focus on social, behavioural, and policy determinants of implementation. Building on the 2022 Prague Declaration on FH paediatric screening, the project translates high-level recommendations into practical, system-level solutions tailored to national contexts².

The closing event will bring together policymakers, EU institutions, public health experts, and patient advocates to discuss how the project’s findings can contribute to ongoing EU health initiatives and policy discussions, including the EU Safe Hearts Plan—where PERFECTO has been explicitly referenced—and the upcoming Council Conclusions on Health Checks expected in 2026.

“Europe has the evidence and the tools. What we need now is coordinated implementation. Early detection of inherited lipid disorders can prevent heart attacks and strokes decades before they occur. PERFECTO findings lay the ground for the wider inherited lipids detection and cardiovascular disease prevention.”

Magdalena Daccord, Chief Executive Officer, FH Europe Foundation



During the project, partners developed and tested new approaches to address the social, behavioural, and policy challenges surrounding FH. A key milestone was the training of FH Ambassadors in Cyprus, strengthening patient engagement and advocacy capacity across the European network. The project also produced an innovative Personalised Communication Model (PCM), developed in collaboration with Romania and piloted in Cyprus, designed to support effective communication with families about genetic cardiovascular risk and early screening.

Research conducted within the project highlighted several barriers to detection, including low awareness of genetic cardiovascular risk, limited recognition that children can be affected, and psychosocial concerns such as stigma or anxiety about inherited conditions. These barriers look different based on a person's age, gender, ethnicity, or socio-economic status; they lead to FH inequities. They can, however, be overcome with a critical role to play for family doctors as trusted entry points for early detection.

PERFECTO not only shows how paediatric FH screening can be realised, its societal return-on-investment model demonstrates the long-term benefits for individuals, families, and healthcare systems, offering policymakers practical tools to support evidence-based decision-making.

The closing event will culminate in a policy paper outlining recommendations for integrating inherited lipid disorder screening into national cardiovascular disease strategies and strengthening cooperation across Europe.

With cardiovascular disease responsible for around one-third of all deaths in Europe, early detection of inherited risk factors offers a clear opportunity to "*Prevent the Preventable.*"

PERFECTO demonstrates that Europe has the knowledge, tools, and collaborative networks needed to support implementation in practice, and lead the way forward to robust and equitable screening, diagnosis and treatment for hyperlipidaemias.

Stakeholders are invited to join the discussion and contribute to shaping the next steps for cardiovascular prevention in Europe.

Practical information:

- **27–28 April 2026**
- **Representation of the State of North Rhine-Westphalia to the European Union**
Rue Montoyer 47, 1000 Brussels, Belgium
- **More information and agenda available here:** <https://perfecto-fh.eu/perfecto-closing-event/>
- **Register for in-person or online participation:**
https://forms.zohopublic.eu/fheuropefoundation1/form/PERFECTOClosureEventRegistration/formperma/wcTld2zdpY93G_cZVDrIkTnl8GBI1bwBA7KT5YB3mw



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References:

1. Gidding SS, Wiegman A, Grosej U, et al. Paediatric familial hypercholesterolaemia screening in Europe: public policy background and recommendations. *Eur J Prev Cardiol.* 2022;29(18):2301-2311. doi:10.1093/eurjpc/zwac200
 2. Bedlington N, Abifadel M, Beger B, et al. The time is now: Achieving FH paediatric screening across Europe - The Prague Declaration. *GMS Health Innov Technol.* 2022;16:Doc04. doi:10.3205/hta000136
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**Advancing
Screening for
Inherited Lipid
Disorders:
Untapped
Potential for Safe
Hearts Plan in
Europe**

27-28 April 2026
Brussels, Belgium (Hybrid)

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