FHSC
EAS Familial
Hypercholesterolaemia
Studies Collaboration

Spring 2025
Issue 31

NEWSLETTER

CONTENTS

EAS FHSC: A Decade of Collaboration, Innovation, and Impact in FH Care

The collaboration has achieved a remarkable growth and impact since its inception in 2015. Starting with a few countries, the collaboration has expanded to encompass 76 countries and 92 National Lead Investigators, collecting data on >80,000 individuals with familial hypercholesterolaemia (FH). This global network represents one of the most comprehensive international collaborations in cardiovascular disease research.

Over its first decade, the FHSC has produced several high-impact publications in prestigious journals including Atherosclerosis, The Lancet, and The Lancet Diabetes & Endocrinology and European Heart journal. Key research milestones include:

- The initial "call to arms" establishing the need for global FH research (Atherosclerosis, 2015)
- Documentation of the collaboration's rationale and design (Atheroscl. Suppl., 2016)
- Comprehensive overview of FH care across 60+ countries (Atherosclerosis, 2018)
- Global perspective on FH in adults (Lancet, 2021)
- Characterisation of FH in children and adolescents (Lancet, 2024)
- Association between BMI, LLM, age and diabetes in FH patients (The Lancet Diabetes & Endocrinology, 2024)
- Analysis of overweight, obesity and CVD in FH (European Heart Journal, 2025)

The collaboration helped shape The Prague Declaration for Paediatric FH Screening, which was subsequently recognised for its excellence through inclusion in the European Union’s Best Practices Portal for Non-Communicable Disease (NCD) prevention (you can access and endorse the declaration here).

EAS FHSC: Progress on Follow-Up Data Collection

The EAS FHSC Coordinating Centre is pleased to report a significant milestone: follow-up data has now been collected for **19,200** individuals with FH in the registry—a 200% increase from last year's figures. This substantial growth demonstrates the exceptional commitment of National Lead Investigators across our global network.

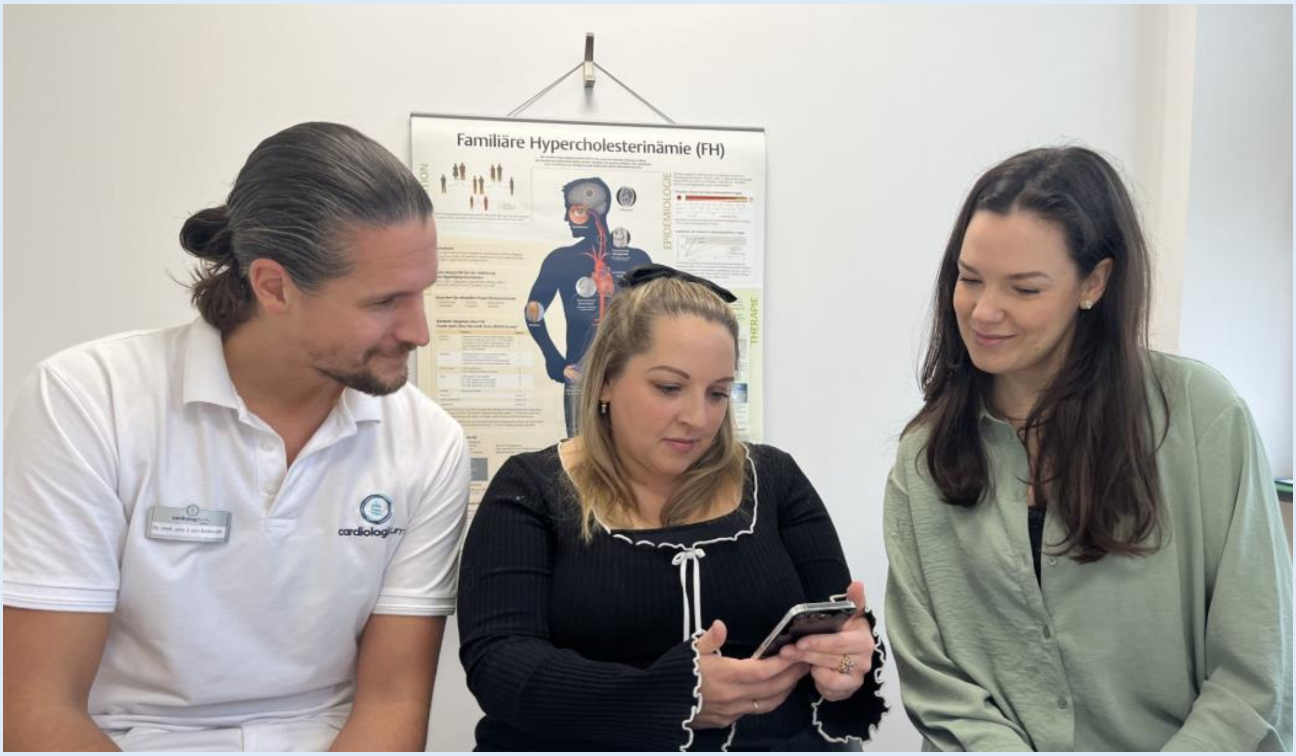
Our team at the Coordinating Centre has worked methodically to harmonise these diverse datasets, creating a standardised resource that will enable robust analysis, including of clinical outcomes, treatment effectiveness, and changes in clinical practice over time.

However, the coordinating centre has **identified specific information gaps in certain fields** that require attention and **will contact contributing NLIs directly** about filling these gaps to strengthen the overall dataset.

To maximise participation, we have **extended the submission deadline to October 2025,** allowing current contributors to enhance their submissions and creating opportunity for additional countries to contribute.

Initial analyses from this comprehensive follow-up dataset will be presented at the FHSC closed meeting in Athens 2026 next year, establishing a foundation for numerous future studies that will directly inform FH patient care.

CaRe High's patient self-management App



In January 2025, the German FH registry CaRe High (Cascade Screening and Registry for High Cholesterol) launched its patient self-management app and enrolled its first patient. This is a significant milestone for the registry and, most importantly, for patients. The CaRe High app streamlines patient engagement, provides clinicians with real-time insights, and empowers patients to take control of their treatment.

With the app's release, the frequency of follow-up interviews has increased. Patients can now complete the baseline questionnaire, yearly follow-ups, and quarterly short surveys via the app. The data is processed directly into the registry database, enhancing patient-centered FH management in Germany. This achievement marks a significant milestone for patients, clinicians, and the German FH community.

Our success was made possible by the support of Amgen GmbH, Novartis Pharma GmbH, and Ultragenyx Germany GmbH, as well as the cooperation with Punktum Digital GmbH for app programming and MaganaMed GmbH as the medical database provider.

The German Vroni-team

Collaboration with the Iraqi Parliament to Improve FH Care.

As part of our efforts to improve care for Familial Hypercholesterolemia (FH) patients in Iraq, we met with Mr. Bassim Al-Gurabi, a member of the health committee in the Iraqi parliament, to discuss the importance of making novel lipid-lowering drugs readily accessible for these patients. We also discussed officially implementing the strategies we have already designed and incorporating them into the health services in Iraq.

The health committee instructed the Iraqi Minister of Health to actively collaborate with the Iraqi Lipid Clinics Network (ILCN) to prioritize FH care. Following this meeting, we met with the Iraqi Minister of Health to discuss how to make our collaboration fruitful and result in actionable steps.

The minister immediately instructed the concerned department in the ministry to take executive steps in this regard.

The ILCN is very pleased to achieve such remarkable progress, which comes after years of dialogue with officials in the ministry.

Mutaz Al-Khnifsawi, National Lead Investigator Iraq

Pioneering Familial Hypercholesterolemia Awareness in Zimbabwe.

BRAVE LITTLE HEARTS ZIMBABWE

IAS

Division of Medicine (Mpilo Hospital Zimbabwe)
in
Collaboration with International Atherescelorisis Society(IAS) and Iraqi Lipid Clinics Network

12 MAY,2025

FAMILIAL HYPERLIPIDEMIA SYMPOSIUM

17:00-18:00

PREVENT,DETECT & TREAT FAMILIAL HYPERLIPIDEMIA

DR GUTU 0773785427
DR GERESS 0777802473

JOIN

HTTPS://US04WEB.ZOOM.US/J/71529192218?PWD=NOEWLD0ARW0Y5PQHUNT9N6JZWSHTSG.1

MODERATOR
DR GERESS
(CARDIOLOGIST)

SPEAKER

Dr Mutaz Al-Sabah
Preventive Cardiologist
President of the Iraqi Lipid Clinics Network.
IAS Board of Directors

ILCN
Iraqi lipid clinics network

In collaboration with the Department of Internal Medicine at Mpilo University Hospital in Zimbabwe, and under the umbrella of the Brave Little Hearts Foundation, we organized the first-ever Familial Hypercholesterolemia (FH) symposium for the department's staff. The event focused on the importance of early detection and appropriate treatment of this genetic lipid disorder, which poses a significant threat to both current and future generations.

This symposium marked a key milestone in the preparations to establish the country's first lipid clinic and to join the Familial Hypercholesterolemia Studies Collaboration (FHSC), an initiative of the European Atherosclerosis Society (EAS).

Mutaz Al-Khnifsawi, National Lead Investigator Iraq

NEWS FROM FH EUROPE FOUNDATION

Call to Action Following EAS 2025 – HoFH and Elevated Lp(a) in the Spotlight

The EAS Congress 2025 in by familial hyperlipidaemias, including HeFH, HoGlasgow marked a significant milestone for the FH Europe Foundation (FHEF) and the wider community affected FH, elevated Lp(a), and FCS. Two particular dates stood out, offering strong visibility and clear calls to action.

On 4 May, the opening day of the Congress, HoFH Awareness Day, launched by FHEF in 2024, was observed. This rare and severe form of familial hypercholesterolaemia was brought into focus for the scientific and clinical audience in attendance. The occasion provided a timely and important opportunity to increase understanding, encourage dialogue, and promote collaboration around HoFH, under the banner of the call to **"Unite 4 HoFH."**

HoFH
AWARENESS DAY

FH Europe Foundation

WEBINAR TRILOGY

Episode I - 27 May
The Inherited Legacy - Family Planning & Caring for Children with HoFH

Episode II - 3 June
The Teenage Rebellion - Transitioning from Childhood to Adulthood with HoFH

Episode III - 10 June
The Future Strikes Back - Living a Full Life with HoFH as an Adult

The following day, 5 May, saw FHEF present the **Lp(a) International Taskforce (ITF)** and its impactful research and advocacy work. The ITF is a multidisciplinary, multistakeholder initiative made up of global experts in lipids, cardiovascular science, health policy, patient advocacy and innovation. Chaired by Prof. Florian Kronenberg, the session featured key insights from the **1st Lp(a) Global Summit**.

Prof. Zanfina Ademi presented findings from a **new cost-effectiveness study on Lp(a) testing in primary prevention**. Marc Rijken, an internationally recognised patient ambassador, shared his lived experience as a member of the ITF. Magdalena Daccord, FHEF CEO, presented the **Brussels International Declaration on Lp(a) Testing and Management**, which was published that very morning in *Atherosclerosis*. All stakeholders are invited to register to the "**HoFH 360°: A New Hope for Every Generation" webinar trilogy**, which brings together leading clinicians and patient voices to share insights on the lifelong impact of HoFH and the latest advancements in diagnosis and care.

Access to the **Brussels Inter. Declaration** is freely available and all are invited to endorse it to help drive early detection of CVD risk factors.

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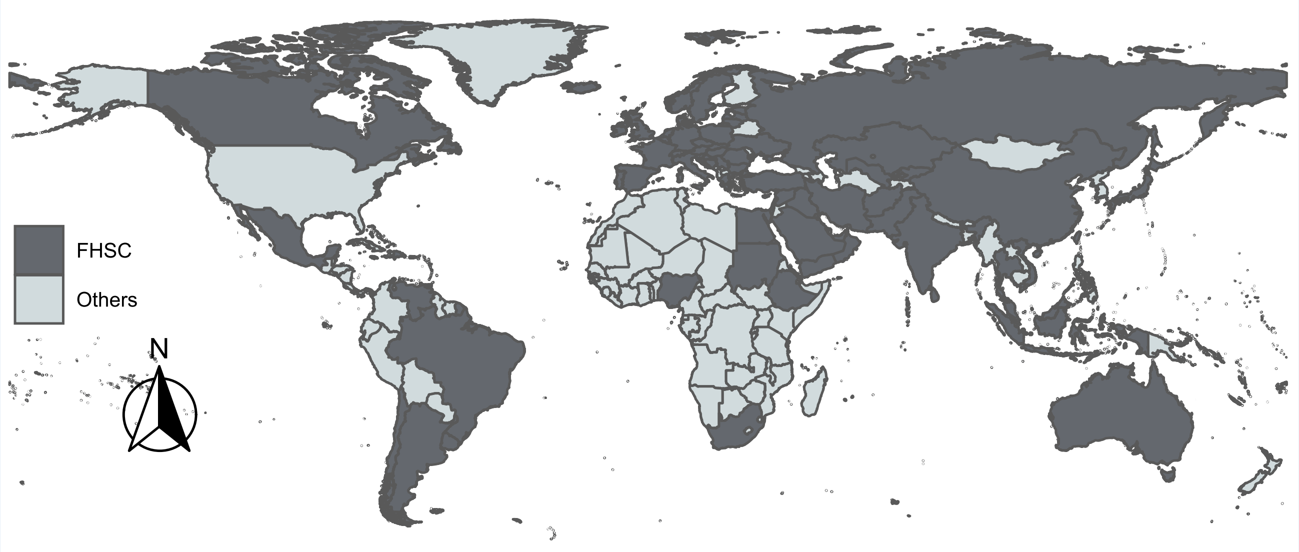
GET INVOLVED



FHSC spans 76 countries and includes 92 National Lead Investigators.
The FHSC Registry includes approx. Approx. 81K cases across 68 countries.

Do you have an interest in FH, collect clinical and/or genetic FH data and are keen to contribute to the EAS FHSC Global Registry (NCT04272697)? If so, we would like to hear from you! For enquires contact info@eas-fhsc.org.

The FHSC Coordinating Centre provides a free essential web-based resource exclusive to FHSC Investigators and their local teams to support entering and managing local-level data and sharing data with the FHSC Global Registry.

Worldwide Directory of Lipid Clinics & Patient Support Groups:
findmylipidclinic.com For more information: Stevens *et al. EAJ* 2022;2:37-40