



FHSC

EAS Familial
Hypercholesterolaemia
Studies Collaboration

Autumn 2023
Issue 25

NEWSLETTER

CONTENTS

FH Awareness 2023
Network & Registry

National Leads' Reports
FH Europe Foundation

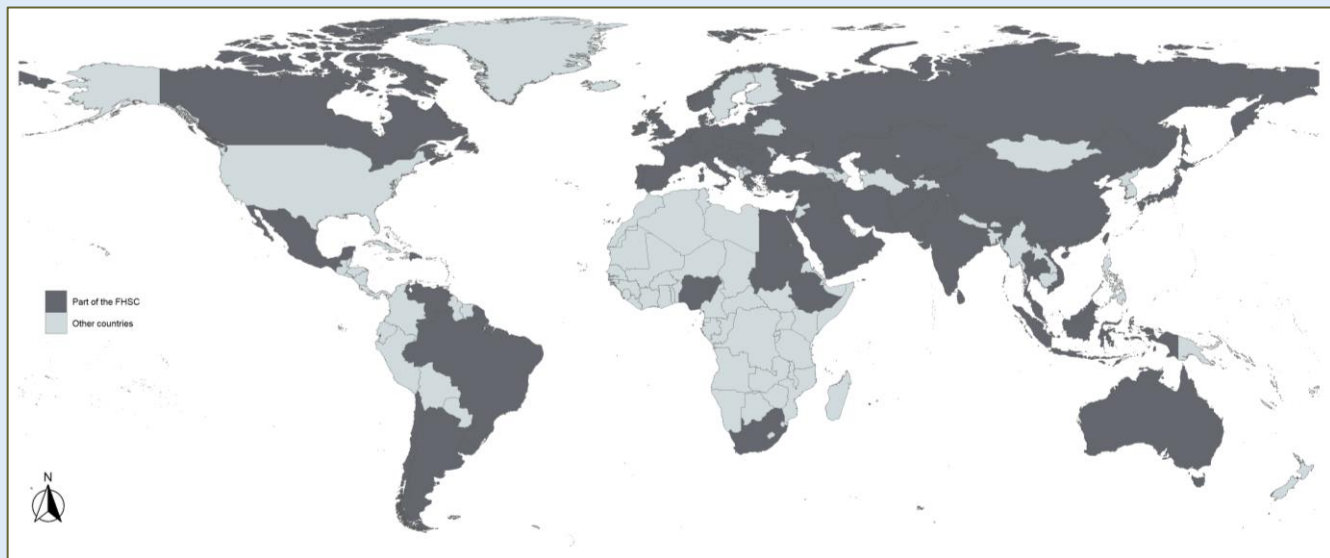
HEADLINES: FH Awareness Campaign 2023

FH TOPICS

- ✓ GENETICS
- ✓ SCREENING
- ✓ IMPORTANCE OF MEASURING LP(a)
- ✓ ACCESS TO TREATMENT
- ✓ CHALLENGES FOR CHILDREN

EAS and FH Europe Foundation collaborate to provide a FH Awareness Webinar Series linked to the annual campaign from 25th – 29th September 2023.

[Click here](#)



The FHSC currently spans **74 countries** and includes **87 [National Lead Investigators](#)**. The FHSC Registry includes **71,718 cases** across **66 countries**.

GET INVOLVED

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** ([CT.gov Identifier: NCT04272697](#))?

If so, we would like to hear from you! For enquires contact info@eas-fhsc.org

More information about the EAS FHSC can be found in these publications:

- [FHSC Study Protocol: 'Pooling and expanding registries of FH'](#)
- [FHSC Survey: 'Overview of the current status of FH care in over 60 countries'](#)
- [FHSC Results: 'A global perspective on FH: Cross-sectional study from the EAS FHSC'](#)

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. Ask the Coordinating Centre for more details.

Worldwide Directory of Lipid Clinics & Patient Support Groups: findmylipidclinic.com

For more information: [Stevens et al. EAJ 2022;2:37-40](#)



FHSC

EAS Familial Hypercholesterolaemia Studies Collaboration

NATIONAL LEAD INVESTIGATORS' REPORTS

Establishment of the first women's lipid clinic in Iraq

The Iraqi Lipid Clinics Network collaborates with the Authority of Health & Medical Education in Imam Hussein Holy Shrine, Iraq to establish the first women's lipid clinic in Iraq, and to our knowledge, the first of its kind in the MENA and African regions.

This unique clinic, located in Khadeejat Al-Kubra Women's Hospital, Karbala City (110km Southwest of Baghdad), provides healthcare services by female clinicians exclusively to female patients suffering from familial lipid disorders. The long-term goal is to narrow the gender gap in healthcare available in this region by overcoming some of the local religious constraints concerning male clinician – female patient interaction.



It is with thanks to Dr. Haydar Al-Abidi, Head of the Authority of Health and Medical Education for making this possible.

National Lead of Iraq Dr. Mutaz Al-Khnifsawi

Interested to contribute an article (FH news, publications, events, etc)?

Please contact: info@eas-fhsc.org

SAVE THE DATE!

The EAS 7th EAS Paediatric Familial Hypercholesterolemia Symposium

Saturday, 25 May 2024 | Lyon France

Topics:

Rare dyslipidemias in children: clinical presentation, genetics and management (LAL-D, FCS and Sitosterolaemia)

Is it time to lower targets for initiation and on treatment LDL-C in children with FH?

How to maximise compliance and adherence to lipid-lowering treatment in adolescents with FH

 **EAS**
92nd Congress

26-29 May 2024 | Lyon, France

Organised by: Noel Peretti, Jeanine Roeters van Lennep, Mafalda Bourbon, Kirsten Holven, Michal Vrablik, Olivier Descamps, Marianne Becker, Urh Grosej, & Steve Humphries
in conjunction with **FH Europe**

FH EUROPE FOUNDATION

Register and Save the Date

We are delighted to invite you to join **FH Europe Foundation** at the upcoming 9th edition of **the Science Summit at the United Nations General Assembly (UNGA78)** in New York.

On Tuesday, September 26th, Dr Marius Geanta, our Trustee and Chair of the Policy and Innovation Advisory Committee, will present in a dedicated session “New Horizons for CVH globally – the role of digitalization and health data” the topic of “**A personalised approach to preventing the preventable using digitalisation and health data**”.

For the full programme [click here](#).

This is a unique opportunity for us to put cardiovascular health (CVH) and inherited lipid conditions on the global health map, with a major Call for Action. We will build on our advocacy journey for familial hypercholesterolaemia (FH) paediatric screening, [the Slovenian High Level Technical Meeting](#), the [Czech EU Presidency meeting on FH screening](#) and the outcome of it – [the Prague Declaration](#), which has been widely endorsed in Europe and beyond. We will also present our new global strategy on tackling Lp(a) and the importance of systematic testing and managing effectively elevated Lp(a) as an independent risk factor associated with cardiovascular diseases (CVD).

The ECHAlliance Global Health Connector two-day event “**Unlocking Solutions for Global Health Challenges**” will take place at the CURE in New York and virtually, on 26-27 September. This internationally important event is a global platform that brings together leaders, scientists, technologists, industry, policymakers, and innovators to promote the role of science in achieving the UN Sustainable Development Goals (SDGs) for a better shared future and to prepare the UN Summit of the Future 2024.

For the full programme and to register (online or in-person) [click here](#).

We hope you can join us!

Chief Executive of FH Europe Foundation Magdalena Daccord