



FHSC

EAS Familial
Hypercholesterolaemia
Studies Collaboration

Winter 2023
Issue 26

NEWSLETTER

CONTENTS

FH Outreach Activity & New Opinion Paper
Network & Registry

National Leads' Reports
FH Europe Foundation

HEADLINES: FH Outreach Activity



KI Dharmayat and CAT Stevens (Coordinating Centre) represented the FHSC at the FH Europe Foundation (FH patient network) Annual Network Meeting, Amsterdam in November. Their presentations emphasised the pivotal role of disease registries and provided an overview of the FHSC findings. The theme "Together Engaged for Change" spurred collaboration among individuals with FH, clinicians, researchers, and industry representatives. The event facilitated dialogue on managing conditions like FH, Lp(a), and FCS. The exchange of expertise reflected a shared commitment to foster positive healthcare change, aligning with both FH Europe Foundation's and the FHSC's mission and values.

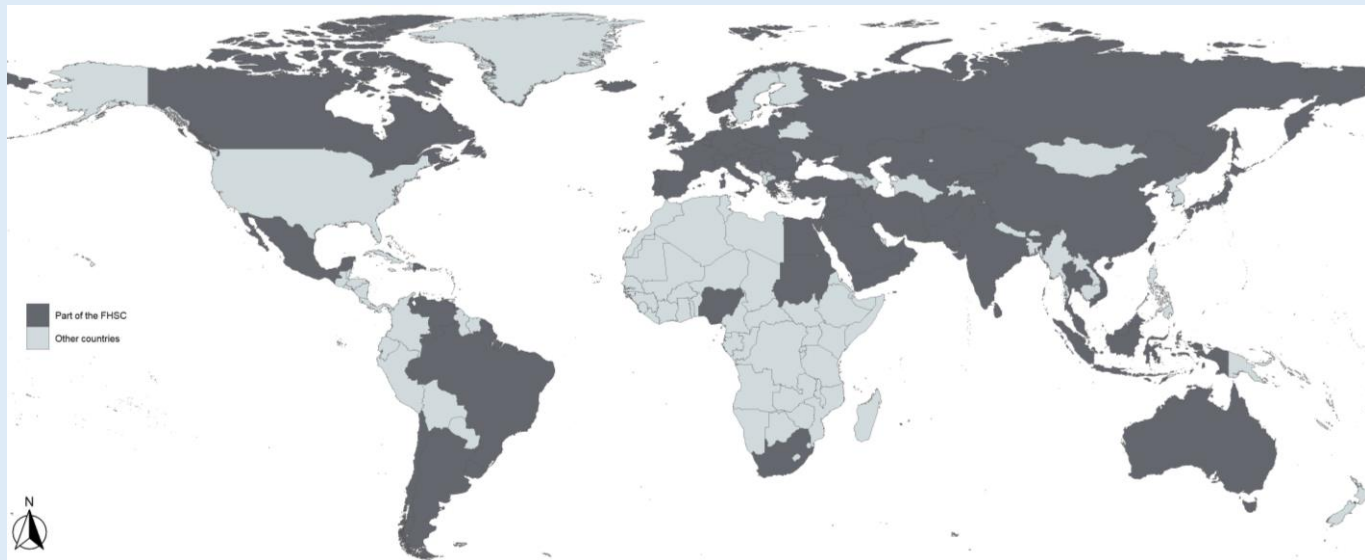
New publication: Opinion Paper 'Overview of a collaborative global effort to address the burden of FH'. *Indian Heart Journal* 2023
<https://doi.org/10.1016/j.ihj.2023.11.005>



FHSC

EAS Familial
Hypercholesterolaemia
Studies Collaboration

GLOBAL NETWORK & REGISTRY



FHSC welcomes Iceland and now spans 75 countries and includes 89 [National Lead Investigators](#). The FHSC Registry includes approx. 72K 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'](#)
- [Overview of a collaborative global effort to address the burden of FH](#)

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](#)

Survey on FH, pregnancy, and breastfeeding for women with FH

Women with FH are often misdiagnosed and undertreated. Treatment time may be interrupted during pregnancy and breastfeeding. In collaboration with FH Europe Foundation, a survey for women with FH is being conducted to improve knowledge on pregnancy and breastfeeding in relation to FH.



The aim is to collect the voices from 1,000 women with FH worldwide. The questionnaire is translated into 17 languages. Help us spread the word about the survey to your female FH patients and colleagues treating patients with FH.

Women with FH can participate in the survey via the following specifications:

- Follow the QR code
- Select preferred language
- Answers to the questionnaire are anonymous
- Takes approximately 10 minutes to complete
- Can be conducted on a mobile phone, tablet or computer

More information can also be found on the webpage of the FH Europe Foundation:
[Women and FH - A Global Research Survey - FH Europe Foundation \(fhf.org\)](https://fhf.org)

If you would like more information or help with distributing the survey in your language, please contact the Principal Investigators:

Dr. Kirsten B. Holven (National Lead of Norway) k.b.holven@medisin.uio.no

Dr. Jeanine Roeters van Lennep j.roetersvanlennep@erasmusmc.nl.

Establishment of the first Women's Hypertension Clinic in Iraq



To continue our fight against cardiovascular diseases by targeting their risk factors, we launched a new initiative in Iraq targeting hypertension in the same way of our past initiative to target severe dyslipidemia.

In September 2022, the World Hypertension League (WHL) published its Call-to-Action paper to increase awareness about hypertension and increase the rate of detection and treatment. In accordance with that paper, we launched this new initiative, 'The National Hypertension Control Program'

to discuss with healthcare providers across Iraq on how to implement this Call-To-Action and achieve its objectives.

Since we prioritise Women's cardiovascular health, our first site was Khadeejat Al-Kubra Women's hospital in Kerbala, Iraq where we established the first Women's Hypertension clinic, as just the first step in a grand project which will continue indefinitely to achieve our long-term goals.

National Lead of Iraq Dr. Mutaz Al-Khnifsawi

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

Please contact: info@eas-fhsc.org

LIPRA: Lipid Registry of Africa

As part of the joint activities of the EAS and its national societies, it is with pleasure, on behalf of the LIPRA Management Board, to announce the newly established LIPRA observational registry project in Africa.

Its purpose is to establish a network and infrastructure of researchers and communications across Africa, to study risk factors and lipid profiles in Africans with premature acute coronary syndrome and their treatment strategies across different African countries.

LIPRA National Leads will collect and contribute data via an e-platform to upload approved Case Report Files from consented participants.

Clinicians and researchers from Fifteen African countries are currently involved in LIPRA. This project has been adopted and supported by the EAS with special thanks to Helena Nielsen Knights for administrative support.

For more information: info@eas-fhsc.org

LIPRA Management Board

**Co-Chair
& Project Manager**



Dr. Ashraf Reda

**FHSC National Lead
of Egypt**

Co-Chair



**Prof. Alexandros D
Tselepis**

**FHSC Co-National
Lead of Greece**

Co-Chair



Prof. Alberto Zambon

**EAS Representative
Italy**

External Advisor



**Dr. Alexander RM
Lyons**

**FHSC Coordinating
Centre, UK**

“Vote Cardiovascular Health 2024” - a once in a lifetime political opportunity for genetic dyslipidaemias

FH Europe Foundation (FHEF) continues its mission to make early screening and detection of genetic CVD risk factors like HeFH, HoFH and elevated Lp(a) on the EU political level. Following two high level meetings under the EU Presidencies in 2021 (Slovenia) and 2022 (Czechia) calling for FH paediatric screening implementation in Europe, this December FHEF's team and Patient Ambassadors will join a 100 people delegation to the EU Parliament calling for a Cardiovascular Health Plan for Europe.

“Vote Cardiovascular Health 2024” is an event organised by the [European Alliance for Cardiovascular Health \(EACH\)](#), of which FHEF has been a Partner since its creation in 2021, highlighting the state of [cardiovascular health, costs, and investments in the EU's 27 countries](#). It is the centre stage from which EACH Partners call for cardiovascular health (CVH) to be high on the policy agenda of the European Parliament when Members of European Parliament (MEP) gather in Strasbourg, France.



The poster features the EACH logo (European Alliance for Cardiovascular Health) in the top right corner. The main title is "Exhibition VOTE CARDIOVASCULAR HEALTH 2024". Below the title, it says "Hosted by" followed by two circular portraits: MEP Elżbieta Katarzyna LUKACJEWSKA and MEP Radka MAXOVÁ. A red button says "Save the date" above the dates "11 - 14 December 2023" and the location "at the European Parliament in Strasbourg". The hashtag "#VOTE HEALTH 2024" is at the bottom left. A red arrow points to "SWAN BAR" and a location icon points to "Churchill Building (WIC)".

Why? - CVD tops the killer leaderboard, causing more than one-third of all deaths in the EU and impacting the lives of some 60 million people. CVD cost the EU an estimated €282 billion in 2021. Cardiovascular and related long-term care accounted for €155 billion (55%) of these costs, equalling 11% of EU health expenditure. However, 80% of all CVDs may be preventable!

The event will be officially launched with an Opening Ceremony moderated on behalf of EACH Secretariat by [Prof Franz Weidinger](#). Following a welcome speech by the hosts - MEP Elżbieta Łukacijewska (PL, EPP) and MEP Radka Maxová (CZ, S&D) - international patient advocates will take to the stage. Among them Marc Rijken, (The Netherlands), FH Europe Foundation's Patient Ambassador with elevated Lp(a), joined by his wife and daughter, will represent the voice of people affected with inherited lipid conditions and CVD risk factors (elevated Lp(a), HeFH, HoFH, and FCS).

Follow #VoteHealth2024 and visit <https://www.cardiovascular-alliance.eu/vote-cardiovascular-health-2024/>

FH Europe Foundation CEO Magdalena Daccord