



FHSC

EAS Familial
Hypercholesterolaemia
Studies Collaboration

Summer 2023
Issue 24

NEWSLETTER

CONTENTS

Steering Committee
Network & Registry

National Leads' Reports

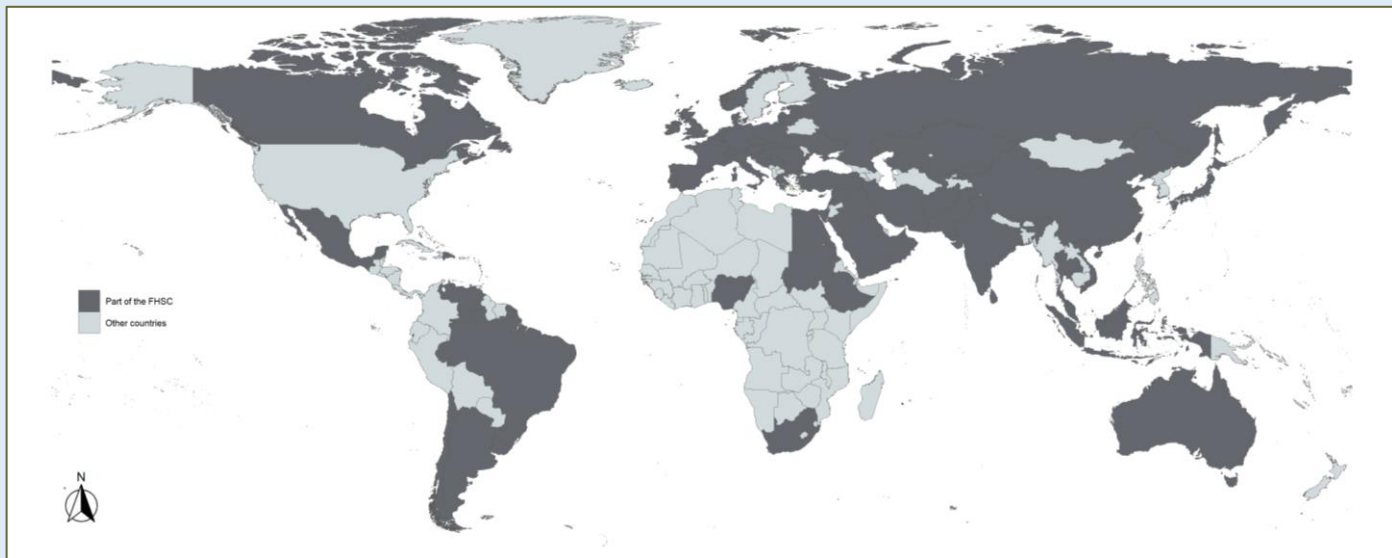
FH Europe's Lp(a) International Task Force
VRONI Study goes North

HEADLINES: Steering Committee Action Points



National Leads to share data, where possible, via the FHSC Registry Website (IDEAPP feature available or Excel templates) on:

- Genetics (by 20th July 2023)
- Follow-ups (by 20th October 2023)
- New baseline fields



The FHSC currently spans 74 countries and includes 87 [National Lead Investigators](#). The FHSC Registry includes 70,000 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](#)

Overcoming Challenges in Collecting Follow-up Data in the FHSC Registry: Exploring the Greek Experience

Established in 2016 by the Hellenic Atherosclerosis Society, the Hellenic FH Registry (HELLAS-FH) has now more than 3,000 patients registered. Also, HELLAS-FH has recorded follow-up data for nearly a third of these patients, contributing significantly to the understanding of FH. Eight papers in peer-reviewed journals have been published up until now and more are undergoing preparation.

Follow-up data plays a crucial role in managing FH, aiding in risk assessment, tracking disease progression, monitoring treatment efficacy, ensuring safety, and contributing to research and policy decisions. Despite several challenges at different levels (site-, patient-, and data collection-associated), the use of digital tools like the FHSC Individual Data Entry Application has been pivotal in overcoming these issues.

Strategies like patient engagement, standardisation of data collection, incentivisation and reminders, close collaboration with healthcare providers, and

use of digital tools have been successfully implemented to improve follow-up data collection. Monthly newsletters, regular investigator meetings, determining author order based on each site activity, and assigning a dedicated physician to closely monitor follow-up progress have served as effective measures, boosting data collection and follow-up efforts.

The experience with HELLAS-FH has emphasised the importance of a collaborative effort involving patients, healthcare providers, researchers, and registry staff. Leveraging technology and adapting to new challenges and patient needs are critical for continued success. Regular evaluation and refinement of data collection processes help maintain data quality and overcome new challenges.

National Lead of Greece Prof. Evangelos Liberopoulos and colleague Dr. Christos Rizos

National Leads of Saudi Arabia Prof. Fahad Alnouri and Brazil Prof. Raul D. Santos published the following review article:

Alnouri F, Santos RD. New Trends and Therapies for Familial Hypercholesterolemia. *J Clin Med*. 2022 Nov 9;11(22):6638. doi: [10.3390/jcm11226638](https://doi.org/10.3390/jcm11226638). PMID: 36431115; PMCID: PMC9696955.

Interested to contribute an article (FH news, publications, events, etc) to the next Newsletter?
Please contact: info@eas-fhsc.org

Establishment of the first lipid clinic in Tanzania (Dar-essalam Lipid Clinic)

In collaboration with the Iraqi Lipid Clinics Network, Muhimbili National Hospital in Tanzania celebrated the opening ceremony of their first lipid clinic on Thursday 15th December.

Muhimbili National Hospital is one of the biggest governmental teaching hospitals in the capital Dar Es Salaam with a capacity of 2500 beds, presenting medical services in different specialties.

This achievement came after collaboration with Prof. Mohamed Janabi, CEO of the hospital whose efforts and contribution were pivotal in making this possible .

Three weeks prior to the opening ceremony, there was a FH symposium arranged for the hospital staff to talk about the prevalence and risk of delayed diagnosis of familial lipid disorders.

The clinic will operate twice a week in the hospital as we agreed one day for adult patients and another for paediatric patients.

This event was part of our international initiative to increase awareness about atherosclerosis prevention and familial lipid disorders recognition in MENA and Africa .

National Lead of Iraq Dr. Mutaz Al-Khnifsawi



FH Europe convenes an International Task Force on Lp(a) to drive change at global level

The current discourse on Lp(a) among many stakeholders across the globe points to the urgent need to encourage a more systematic and structured approach to testing the population, following guidelines, to decrease overall CVD risk / prevent CVD from high levels of Lp(a). The EAS consensus statement and other guidelines underline that everyone should be tested once in a lifetime. An enabling policy environment is crucial for governments to be able to deliver on CVD prevention, health innovation, and to ensure optimal and swift access for people living with elevated Lp(a).

To address this, FH Europe has recently embarked on the preparation of an ambitious global strategy and roadmap on Lp(a), setting up an International Task Force of experts from several different disciplines to contribute to this. This Task Force met for the first time this month and will finalise its work at a face-to-face meeting in the frame-

work of the ESC Congress in Amsterdam at the end of August. The aim is to launch the strategy in January 2024, however a key milestone before that is a Scientific Summit in the framework of the United Nations General Assembly, during which FH Europe will present the need for much more policy attention to the global burden of Lp(a) and how this can be effectively tackled, to save lives, and also to reduce pressure on overstretched health systems.

FH Europe also contributed to the following article:

Watts, G.F., Gidding, S.S., Hegele, R.A. *et al.* International Atherosclerosis Society guidance for implementing best practice in the care of familial hypercholesterolaemia. *Nat Rev Cardiol* (2023). <https://doi.org/10.1038/s41569-023-00892-0>

FH Europe CEO Magdalena Daccord

Recording of Webinar

EAS 2023: Updates from EAS FHSC - the global registry



**Nicola
Bedlington**
(Chair)



**Kanika I.
Dharmayat**



**Ass. Prof. Fotios
Barkas**



**Dr Amany
Elshorbagy**



**Dr Alexander RM
Lyons**



The VRONI Study goes North

VRONI is a screening program for FH in children aged 5 to 14 years and was successfully launched in 2021 as part of the DigiMed project in Bavaria, Germany. Enrolment is conducted by paediatricians with support of their local professional organisation BVKJ. The screening for FH follows a two-step approach: first LDL-cholesterol is measured centrally followed by a genetic analysis for cases ≥ 130 mg/dL (3.35 mmol/L). FH-positive children are registered centrally and treated by specialised paediatricians and paediatric cardiologists. Furthermore, certified training centres offer affected families FH-focused training courses.

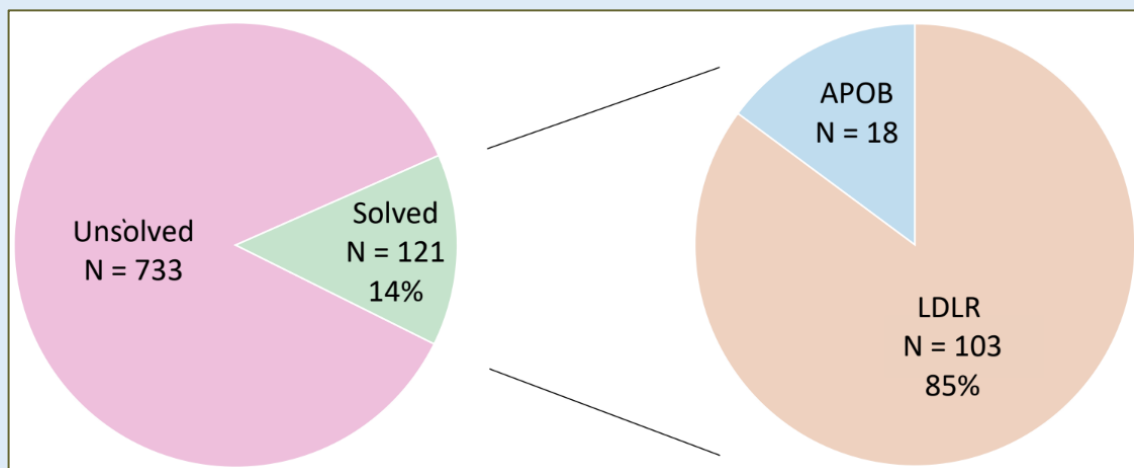
- over 13,000 enrollments (aged 5 to 14 years)
- about 7.3% with LDL-C ≥ 130 mg/dl [3.35 mmol/l]
- 121 children with genetically confirmed FH (familial hypercholesterolemia)

©MYVRONI.DE

For first-degree relatives of FH-positive children, reverse cascade screening is facilitated to identify affected family members. To date, more than 480 paediatricians in Bavaria screened over 13,000 children with 7.3% of them exceeding the predefined LDL-C threshold. Overall 120 children with pathogenic FH-mutations were identified by VRONI in Bavaria.

Together with the German Cardiac Society (DGK) and the Deutsche Herzstiftung preparations are underway for VRONI to go North. In detail, the fully implemented FH screening strategy in Bavaria will be expanded to the northern parts of Germany in close collaboration with Professor Thomas Danne and Professor Olga Kordonouri in Hannover.

Overall VRONI aims to incorporate molecular and clinical diagnostics into a systematic effort to identify individuals with FH early on, followed by a multidisciplinary treatment approach, spanning patient education and counselling as well as regular follow-up assessments and medical therapy. "Going North", VRONI continues to lay the foundation for implementing population wide FH screening into the routine care of children in Germany.



Overview of the genetic analysis performed on the first 854 cases with elevated LDL-cholesterol in VRONI. Green represents the cases with pathogenic variants for monogenic FH, 85% of which were located in the LDL-receptor-gene.