

NEWSLETTER

Issue 23 | March 2023

Issue 23

Headlines: FHSC prepare for their Closed Steering Meeting. FHSC welcomes new National Leads.

Global Network, Registry, and Directory.

Representation at 91st EAS Congress 2023

National Lead Investigators' Reports.

FH Europe – European FH patient network.

FH Studies Collaboration

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[#fhscglobalregistry](https://twitter.com/fhscglobalregistry)

FHSC prepare for their Closed Steering Meeting



The FHSC prepare for their Steering Committee Closed Annual Meeting to be held on Sunday 21st May at the [91st EAS Congress](#) (May 21-24, 2023) at Rosengarten Mannheim Rosengartenpl. 2, 68161 Mannheim, Germany.

FHSC National Lead Investigators will attend the Steering Meeting, by invitation only, to be briefed by the Coordinating Centre on the progress of the global FH registry project and unpublished results, and to participate in scientific discussions to help drive the project.

FHSC welcomes new National Lead Investigators

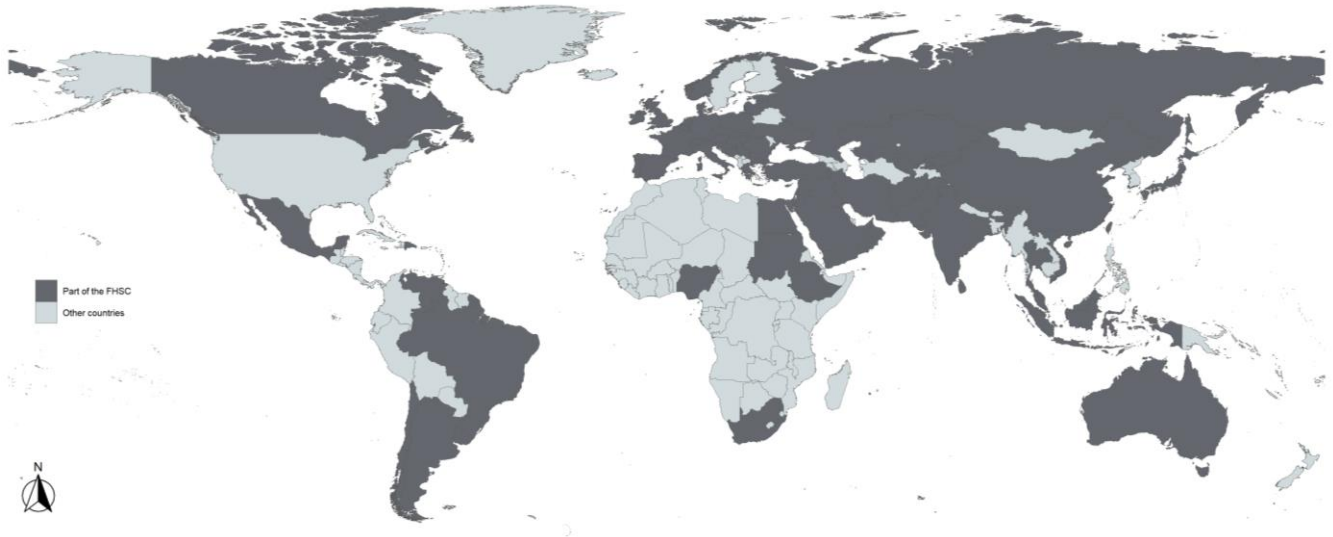


Dr. Tigist Worku Lemma & Dr. Tigist Sileshi
Ethiopia



Associate Prof. Liam R Brunham
Canada

The EAS FHSC now spans 75 countries and includes 88 Lead Investigators; specifically the National Lead Investigators are listed [here](#). EAS FHSC Registry includes 69,776 cases across 66 countries thus far.



Become part of the expanding EAS FHSC

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.

Contribute to the Worldwide Directory of Lipid Clinics & Patient Support Groups:

findmylipidclinic.com

Follow link above to register your lipid clinic and/or patient support group and follow link below for more information

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

Five abstracts on FHSC registry results accepted at the [91st EAS Congress](#) (May 21-24, 2023) at Rosengarten Mannheim Rosengartenpl. 2, 68161 Mannheim, Germany. Visit the EAS to download the [Congress Programme](#).

GENETICS OF DYSLIPIDEMIAS SESSION

How are Children and adolescents with Familial Hypercholesterolaemia detected globally? Analysis from the FHSC Registry on over 11,800 participants from 48 countries

– This talk will discuss the disparities in FH diagnosis across non-high vs. high-income-world regions, including application of genetic testing and how this may change the odds of FH detection in children/adolescents.

FH SESSION

Global prevalence of overweight and obesity among paediatric and adult patients with homozygous or heterozygous familial hypercholesterolaemia, and association with coronary artery disease

– This talk will discuss the role of obesity as an independent predictor of CAD in adults and children with HeFH or HoFH, and the importance of addressing obesity to reduce risk in FH.

SCIENCE AT A GLANCE SESSION

Obesity and statin use may impact the prevalence of diabetes in familial hypercholesterolaemia: A worldwide cross-sectional study by the EAS Familial Hypercholesterolaemia Studies Collaboration (FHSC)

– This talk will discuss the prevalence of type II diabetes with aging and associated factors body-mass-index and statins in adults with HeFH, and importance of reducing BMI to mitigate risk in FH.

Approaches to LDL-C management in Children and Adolescents with Familial Hypercholesterolaemia: Analysis on over 3000 individuals receiving lipid-lowering medication in the FHSC Registry

– This talk will discuss treatment with statins and ezetimibe, and need for combination therapy, and results of recommended LDL-cholesterol goal attainment to reduce ASCVD risk in children/adolescents.

Lipoprotein (a) and atherosclerotic cardiovascular disease in adults with heterozygous familial hypercholesterolaemia: a cross-sectional study from the EAS Familial Hypercholesterolaemia Studies Collaboration (FHSC)

– This talk will discuss the independent association of Lp(a) on CAD presence in adults with HeFH, and importance of treating Lp(a) to reduce risk in FH.

FHSC National Leads Dr. Sadiq of Pakistan and Prof. Groselj of Slovenia co-authored this article (abstract below) in *The Lancet Regional Health - Southeast Asia*. [Available online](#) 20 February 2023, 100163

Mapping of familial hypercholesterolemia and dyslipidemias basic management infrastructure in Pakistan: a cross-sectional study

Fouzia Sadiq, Saeed Shafi, Jaka Sikonja, Madeeha Khan, Quratul Ain, Mohammad Iqbal Khan, Habibur Rehman, Matej Mlinaric, Samuel S. Gidding, Urh Groselj, on behalf of PAKISTAN Familial Hypercholesterolemia Collaborators.

Background - FH is an autosomal inherited disorder characterised by elevated low-density lipoprotein cholesterol and premature cardiovascular events. Despite being declared as a public health priority, FH remains highly underdiagnosed, generally due to the lack of awareness and shortcomings in the available infrastructure, particularly in lower income countries.

Methods - To map the existing infrastructure for the management of FH, a survey was conducted among 128 physicians (cardiologists, paediatricians, endocrinologists, and internal medicine specialists) from different regions of Pakistan.

Findings - The respondents encountered a limited number of adults or children with diagnosed FH. A very small proportion of the population had access to free cholesterol and genetic testing even when indicated by a physician. In general, cascade screening of the relatives was not performed. Uniform diagnostic criteria for FH had not been established even within the same institution or province. The use of statins and ezetimibe in addition to lifestyle changes were the most common recommended treatment option for FH patients. The respondents considered lack of financial resources as a major barrier for the management of FH and stressed on taking relevant measures for a uniform FH screening programs around the country.

Interpretation - National FH screening programmes are not in place worldwide hence FH is commonly undiagnosed, and many individuals are at a high risk for cardiovascular diseases. Timely screening of population for FH requires knowledge about FH among the clinicians and the availability of fundamental infrastructure coupled with sufficient financial resources.



FREE WEBINAR

Beat the Odds of an Early Heart Attack: How to communicate Lp(a) risks to your doctor effectively

Thursday, 23 March
17-18.00 CET

Register:
bit.ly/LpaAwarenessDay2023

With the 2nd international **Lp(a) Awareness Day** fast approaching, FH Europe Patient Ambassadors are sharing their experiences with Lp(a) from diagnosis to day-to-day living.

Join us on Thursday, March 23rd at a special, free webinar, titled ***Beat the Odds of an Early Heart Attack: How to communicate Lp(a) risks to your doctor*** effectively, where we will cover through the Lp(a) patients' lens the following topics:

- **Am I at risk? Why should I care about my Lp(a) levels?**
- **What exactly is high Lp(a) and how high is actually high?**
- **Are Lp(a) levels tested routinely?**
- **How to advocate for my Lp(a) test?**
- **I've been diagnosed with high levels of Lp(a)... what next?**

We will also provide the tools you need to ensure clear and effective communication with your doctor. Sadly, support for people with high Lp(a) can be inconsistent, and knowing what to request and how to do it can help ensure positive outcomes.

We have ***fantastic four*** Lp(a) Patient Ambassadors who will be sharing their experiences:

- **Emma Broome (UK), who will be moderating**
- **J-P Corry (Ireland)**
- **Janine Shipton (Switzerland)**
- **Marc Rijken (Netherlands)**

with the expert clinical support from **Professor Florian Kronenberg (Austria)**.

Register and join us on Thursday, 23rd March at 17:00 CET to learn more!

<https://bit.ly/LpaAwarenessDay2023>



Magda Daccord, FH Europe Chief Executive