

NEWSLETTER

Issue 21 | September 2022

Issue 21

In this Issue:

Headlines: FHSC expansion to date

FHSC Global Network and Registry, & findmylipidclinic.com

FHSC Steering Committee Closed Annual Meeting 2023

Other FH News

FHSC National Lead Investigators' Reports

FH Europe - The European FH Patient Network

FH Studies Collaboration

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Follow us:

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

FHSC welcomes new National Leads Investigators

Dr. Khalil Ahmad Ahrari
Afghanistan



Dr. Maxima Mendez Castillo
Dominican Republic



Appointment in progress
Jordan



Dr. Marianne Becker
Luxembourg



Dr. Thushara Matthias
Sri Lanka



Assoc. Prof. Ahmed Suliman
Sudan



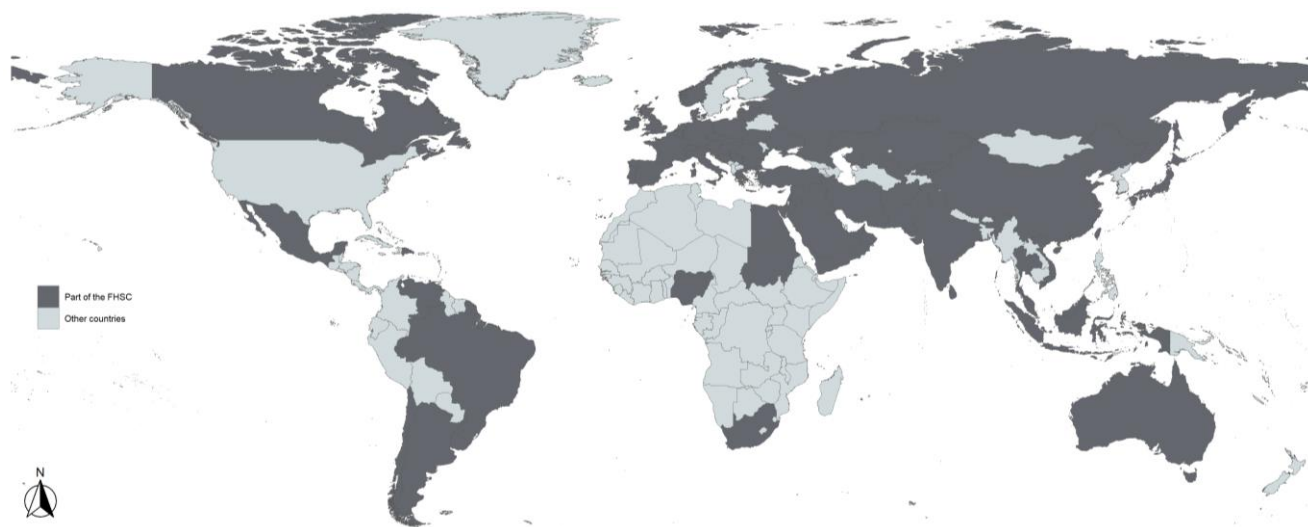
Dr. Rahaf Abood
Syria



Dr. Khalid Aladeeb
Yemen



The EAS FHSC now spans 74 countries (shaded map) and includes 87 Lead Investigators; specifically the National Lead Investigators are listed [here](#). EAS FHSC Registry includes 68,947 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 to register your lipid clinic and/or patient support group

The next FHSC Steering Committee Closed Annual Meeting, exclusive to FHSC National Lead Investigators, will take place on Sunday morning, **21st May 2023** at the [91st EAS Congress \(21-24th May\) in the city of Mannheim, Germany](#).

FHSC National Lead Investigators will receive a personal invitation to attend this closed meeting from the EAS in due course, and are urged to save the date in their diaries in the meantime.



OTHER FH NEWS

The recent International FH Awareness Day took place on Saturday 24th September 2022.

Please follow this link for details

https://www.eas-society.org/page/fh_week_2022

Addis Ababa Lipid Clinic, Ethiopia

In September 2022 as part of our FH Awareness week activities, we celebrated the opening ceremony of the first lipid clinic in Black Lion Hospital (largest teaching hospital in Ethiopia) with our colleagues (photo). This achievement resulted from collaboration with our colleagues Dr. Tigist worku lemma and Dr. Tigist Seleshi that led the initiative in that region.

This opening ceremony proceeded an FH symposium two months earlier which highlighted the importance of establishing such clinics aiming for early detection and appropriate treatment of patients with familial lipid disorders and sharing of knowledge among both HCPs and the public.



Dr. Mutaz Alkhnifsawi
National Lead Investigator of Iraq

Establishment of the first FH Registry in Sri Lanka (SLFHR)

We established the first Sri Lankan FH Registry (SLFHR) in 2022 after obtaining ethical clearance from the Ethics Review Committee of the University of Sri Jayewardenepura. The SLFHR is led by Dr. Matthias, Senior Lecturer in Medicine at the Department of Medicine, Faculty of Medical Sciences, University of Sri Jayewardenepura, and appointed FHSC National Lead Investigator of Sri Lanka.

The prevalence of FH in Sri Lanka is presently unknown and there are limited published case series and case reports. Presently a study has just been completed at the Colombo South Teaching Hospital to identify the prevalence using a laboratory surveillance method and its results will be published in a future article.

We aim to recruit patients to the registry with follow ups to study in detail the epidemiology, complications, and outcome of FH patients in Sri Lanka. At present we are targeting patients from the main cities, with plans to expand to the entire country.

Dr. Thushara Matthias
National Lead Investigator of Sri Lanka.

Recent FH activities in Saudi Arabia:

We have translated the two booklets by Heart UK dedicated to children with FH 'My family, FH and me' and 'FH and me' into the Arabic language. We obtained all the legal permissions from Heart UK, thanks to Professor Steve Humphries. These booklets were provided to the Arabian Gulf colleagues in Bahrain, Kuwait, Oman, Saudi Arabia and the United Arab Emirates and were distributed to FH patients free of charge.

We have published a paper entitled 'Identification of Novel and Known LDLR Variants Triggering Severe Familial Hypercholesterolemia in Saudi Families' in *Current Vascular Pharmacology Journal* doi: 10.2174/1570161120666220304101606.

Dr. Fahad Alnouri
National Lead Investigator of Saudi Arabia.

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

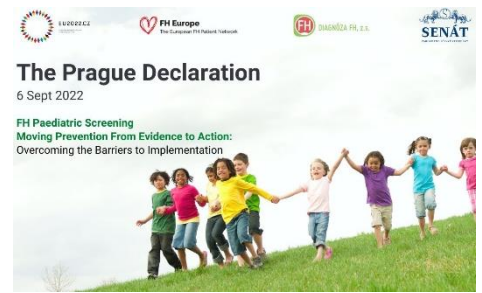
The Prague Declaration – moving towards systematic and universal FH paediatric screening

The Prague Declaration is a political document with seven specific asks for national and European Union policymakers and decision-makers as a result of the Czech EU Presidency meeting on FH Paediatric Screening at the Senate in Prague (6th September 2022). It builds further on the foundation laid during the technical meeting of the Slovenian EU Presidency in October 2021, and [the outcome paper published in the European Journal of Preventive Cardiology](#) only a day prior to the Prague event.

Entitled “FH Paediatric screening – moving prevention from evidence to action: overcoming the barriers to implementation”, the meeting was organised by FH Europe and Diagnóza FH, it’s Czech network member organisation. It convened decision-makers and thought leaders including the Czech Health Deputy Minister, the Chair of the Healthcare Committee of the Senate, representatives of the European Commission, the World Health Organisation (WHO), key European public health institutions, scientific and medical experts, and patient ambassadors.

Widely endorsed, from World Heart Federation (WHF), EAS, EAS FHSC, IAS to national organisations, the declaration demonstrates great collaboration and strengthens joint efforts to making early FH detection a reality. The renewed energy and commitment to advocate for early FH screening was very visible during the FH Awareness Day (24th September), with a public call for action from WFH to WHO.

With the upcoming World Heart Day (29th September), we invite you to support the Declaration by adding your organisation/your name as a signatory [here](#).



Magda Daccord,
FH Europe Chief Executive



Individuals in the community that have signed so far:

- | | | | | | | | |
|--------------------|--------------------------|---------------------------|---------------------|------------------|-------------------------|--------------------------|---------------------|
| Yara Abou khaili | Ana-Silvia Corlan | Marianne Becker | Andrea Muntean | Patricia Petric | Carine Ayoub | Yara Azar | Younna Ghaleb |
| Lovin Maria | Monica Dugăşescu | Marianne AbiFadel | Dorina Popa | Branescu Grogina | Andreea Dinu | Kristyna Cillikova | Gabriela Serbanescu |
| Alexandrea Diana | Marian Croitoru | Florina Croitoru | Garmina Georgescu | Elena Popa | Adriana Croitoru | Adriana Boata | Andra Serban |
| Carmen Paulus | Maria Ferreira | Beatriz Miranda | Ana Catarina Alves | Joana Rita Chora | Ana Medeiros | Rafael Graça | Catherine Boileau |
| Mafalda Bourbon | Lorenzo IUGHETTI | Gustav Latkovskis | Teresa Lawless | Albert Wiegman | Quitéria Rato | Mohammed Dhamin Alaneeth | Madalena Daccord |
| Margus Vilgimaa | Mohammed Dhamin Alaneeth | Lorraine Priestley-Samham | ATHANASIOS PALLIDIS | Anke Venrood | Evangelios Liberopoulos | Paraskevi Georgioudi | Dragos Vinereanu |
| Thanh Huong Truong | Ngoc Thanh Kim | John Burnett | SARIAD OSAMA ALRIL | Musaz Akhifshavi | Noel Peretti | Dan Gata | Tomas Freiblger |
| Michal Vrabilik | Vercoureux Bernard | Urh Grossej | Sarah Qureshi | György Batori | Kausik Ray | J-P Corry | |