

# EAS FHSC NEWSLETTER

Issue 18  
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## Issue 18

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## FHSC Prepare for their Closed Annual Meeting

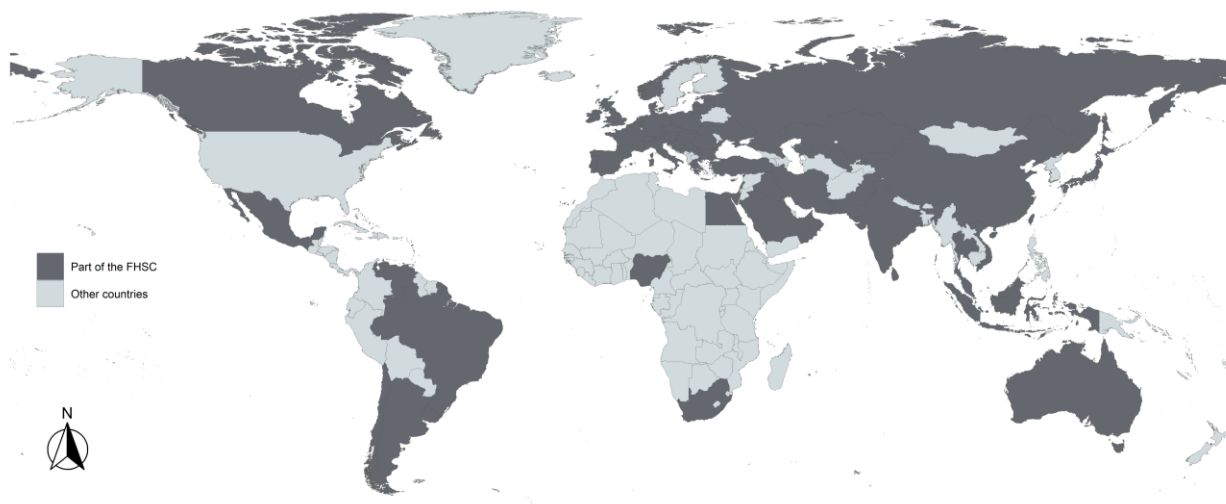
**EAS Familial Hypercholesterolaemia Studies  
Collaboration (FHSC)  
are progressing with preparations for the  
FHSC Steering Committee Closed (exclusive to  
invitations only) Annual Meeting**

**This Closed Meeting (of an estimated 100 invitees)  
will be held on the morning of  
Sunday 22<sup>nd</sup> May 2022**



**In association with the  
90<sup>th</sup> EAS Congress 22<sup>nd</sup> – 25<sup>th</sup> May 2022, Milan, Italy**

The EAS FHSC now spans 67 countries (see shaded map below) and includes 80 Lead Investigators; specifically the National Lead Investigators are listed [here](#). EAS FHSC Registry includes 67,804 cases across 66 countries.



The EAS FHSC welcomes Dr. Ximena Reyes as the new National Lead Investigator of Uruguay and Dr. Diogo Cruz as the new co-National Lead Investigator of Portugal.

## 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](mailto:info@eas-fhsc.org)

**More information about the EAS FHSC can be found in these open-access 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 '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.

## An international initiative for FH awareness in MENA and African region

In January 2021, the Iraqi Lipid Clinics Network launched an initiative, welcomed by the international FH community, to increase FH awareness in MENA and the African region, and help these countries establish lipid clinics which lacked these.

Our lipid clinics, in addition to providing a specialised healthcare service for FH patients, also provide education for both healthcare professionals and the public about FH to improve awareness.

MENA and the African region have political challenges which after months of in-depth discussions and dialogues, we had to overcome – with the patients' interests as priority.

By March 2021, we successfully established the Damascus Lipid Clinic, Syria, and then by September, we established both the Khartoum lipid clinic, Sudan and the Amman lipid clinic, Jordan as we celebrated The World Heart Day, and then the Mogadishu lipid clinic, Somalia by November.

It is not the end of our success story, we continue working hard to open more lipid clinics in these deprived regions.



**Dr. Mutaz Alkhnifawi,**  
FHSC National Lead Investigator of Iraq

## FHCARE Singapore

Our FHCARE team was recently awarded funding in Singapore to try to scale up the work that we are doing for FH. Ministry of Health is interested in Precision Medicine and so looking at FH for this.

**Associate Prof. Subramaniam Tavintharan,**  
FHSC National Lead Investigator of Singapore



**FHCARE**  
**F**amilial **H**ypercholesterolemia:  
**C**ase identification,  
**A**ssessment,  
**R**eduction in adverse  
**E**vents

## Five highlights from 2021 to build on for FH patients' community



Despite the uncertainties and difficulties in 2021, FH Europe had a very positive year. Although those have been very intense 12 months, the organisation has made new alliances and delivered many impactful events.

FH Europe internally carried out a major strategic review and developed a fresh [Guiding Purpose and Vision](#) which has confirmed our coverage of all inherited lipid conditions and given us enhanced focus on our most important objectives. Alongside our [Scientific Advisory Committee](#), we also created a new [Policy Advisory Committee](#) to work jointly on implementing the research findings through health policies. Our Network continues to grow, and this year we have welcomed [five new member organisations](#) - two from Lithuania, and one from Belgium, Bulgaria, and Israel. We were also delighted to participate in the launch of EACH, the [European Alliance for Cardiovascular Health](#) and join the [European Patients' Forum](#) as a member.

The most important and most exciting development was the [push towards paediatric screening for FH in Europe](#) that started with our earlier successful submission to the European

Commission Best Practice Portal and continued with the very successful high level [Technical Meeting on paediatric FH screening](#) under the Slovenian presidency of the Council of the EU. We are now seeing further developments from this policy paper publication and national support in implementation. We are confident that the generated momentum can be sustained through 2022 and beyond.

In the new year we will be strengthening the participation of patients with new patient trustees and a Patient Advisory Council as well as Patient Ambassadors.

We thank EAS FHSC for the ongoing collaboration and support in making 2021 a year to remember and taking us closer to fulfilling our joint mission.

