



# EAS FHSC NEWSLETTER

Issue 14, November 2020

## Issue 14

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## The Latest

### EAS FHSC Steering Committee Annual Meeting 2020

The FHSC Steering Committee Annual Closed Meeting 2020 took place on Sunday 4<sup>th</sup> October in conjunction with the 88<sup>th</sup> EAS Congress.



The Meeting was well attended and well received with all domains scoring on average above 4.5 (5 = excellent) in a feedback survey as shown in the Graph above. The response rate to the survey among participants was 62% (46 responses of 74 attendees). Thank you to those who attended this Meeting and to those who participated in the survey and shared your comments. This information is very useful for improving the organisation and delivery of future meetings.

**Next FHSC Annual Closed Meeting takes place on  
Sunday 30<sup>th</sup> May 2021, 09:00 – 13:00 hrs CET**

*In conjunction with*

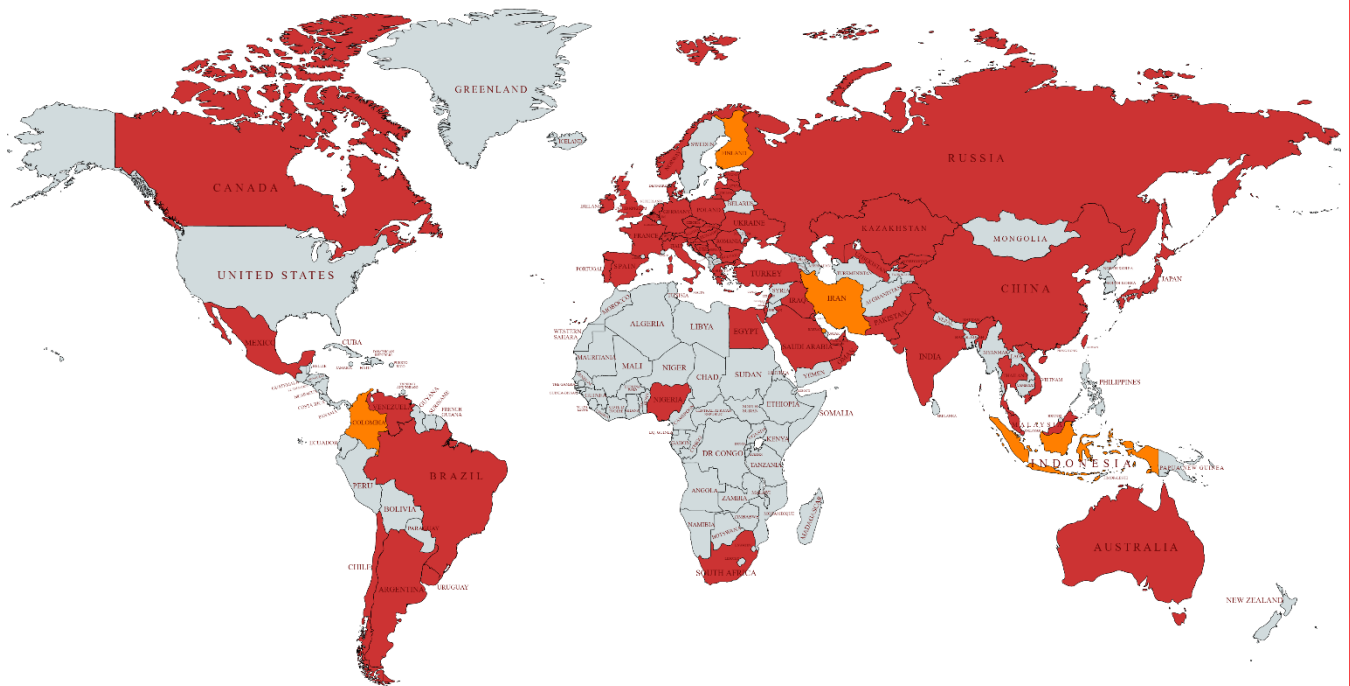
**89<sup>th</sup> EAS Congress on 30<sup>th</sup> May – 2nd June 2021, Helsinki, Finland**

The EAS encourages abstract submission by 12<sup>th</sup> January 2021

- Congress website: <https://eascongress2021.com/>
- Abstract submission: <https://eascongress2021.com/abstracts/abstract-submission/>
- Plenary programme: <https://eascongress2021.com/programme/plenary-programme/>

## EAS FHSC Global Network and Registry

**Eighty-three FHSC Lead Investigators**, with the National Lead Investigators listed [here](#), span **68 countries** of which 63 have contributed (**red**) to the FHSC Global Registry thus far and contributions are expected from others (**orange**) in the network as shown in the shaded map.



**Approximately 63.5K FH Cases Registered Across 63 Countries (Shaded Red)**

## Become part of the 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](https://ct.gov/Identifier/NCT04272697))?

If so, the **FHSC Coordinating Centre** would like to hear from you!

For enquires contact [coordinator@eas-fhsc.org](mailto:coordinator@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 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.

## Latest Software Innovation of the FHSC



findmylipidclinic.com

*Searching ...***New** Web-based Worldwide Directory of Lipid Clinics

This website directory is freely-available to the public to search for **lipid clinics**, **specialist clinicians** and **patient support groups** nearby their location.

The goal is to bridge the gap of communication between patients or potential patients with dyslipidemias and their relatives with specialist practices and practitioners in the field.

This website application is brought to you by the FHSC Coordinating Centre with contributions from the FHSC Network to populate the directory and is supported by 'FH Europe – The European FH Patient Network'. This website will soon be available in 28 languages in addition to English for worldwide accessibility.

This website has been security tested and approved, GDPR approved, confirmed no copyright infringement, and the domain name secured by Imperial College London.

This website is live and in the final stages of development, and we therefore invite specialist practitioners to register your lipid clinic on this worldwide directory by contacting us via [easfhsc@imperial.ac.uk](mailto:easfhsc@imperial.ac.uk). We would be very grateful for your contribution!

## FHSC Call for FH Data on Children

The FHSC Coordinating Centre announces a Call for FHSC National Lead Investigators to submit and update their local FH datasets on children (aged <18 years old) via the FHSC Registry Website (exclusive link provided to you previously). This Call is associated with the FHSC study on children with FH in accordance with the data analysis plans.

Contact the Coordinating Centre for further details and to answer queries  
[coordinator@eas-fhsc.org](mailto:coordinator@eas-fhsc.org)

## Article by BBC News

British Broadcast Corporation (BBC) News released an article (15<sup>th</sup> November) that may be of interest entitled 'Most statin problems caused by mysterious 'nocebo effect', study suggests'.

Access full article free via <https://www.bbc.co.uk/news/health-54951648>

## Kazakhstan FH Registry Launch 2020



We started the Kazakhstan FH Registry in February 2020 and officially joined the EAS FHSC at its inception. I am Professor Kairat Davletov, Director of the Research Health Institute (Al-Farabi Kazakh National University, Almaty, Republic of Kazakhstan), and have been appointed National Lead Investigator of Kazakhstan.

We have enrolled 52 patients with a diagnosis of FH, despite the challenges of the COVID-19 pandemic. Our initiative to expand the Kazakhstan FH Registry to other regions over the country has been met with interest and enthusiasm, and at present we have three centres enrolled thus far.

Our goal is to develop and implement FH Screening and Cholesterol Awareness Programmes in state-run health programs and we are working on achieving this goal.

We thank the FHSC Coordinating Centre and Global Network for this opportunity to participate in such important research.



**Prof. Kairat Davletov,**  
**FHSC NLI of Kazakhstan.**

Contribution by Dr. Dushpanova Anar.

## Iraqi Lipid Clinics Network has Launched a New Programme



During FH Awareness Day on 24th September, the Iraqi Lipid Clinics Network officially announced the launch of a new FH Programme aimed at the people of Iraq planning to start a family by aiming to provide a better life for their children in terms of FH Diagnosis.

This announcement came in the form of a video broadcast, after more than a year of preparation and fruitful discussions with the Iraqi Ministry of Health, and this FH Programme is the first of its kind in the world.

Our video message was broadcasted in two types of Arabic language to the people of Iraq; for those living in the City Centres and others living in rural areas.

These broadcasts are available via the links below.

The video in formal Arabic:  
<https://www.youtube.com/watch?v=FWwoW6vz9Nk&t=70s>

The video in informal Arabic:  
[https://www.youtube.com/watch?v=xOuZ\\_JrCF\\_o&t=5s](https://www.youtube.com/watch?v=xOuZ_JrCF_o&t=5s)



**Dr. Mutaz Al-khnifawi,**  
**FHSC NLI of Iraq.**

Interested to contribute an article (FH news, publications, events, etc) to the next EAS FHSC Newsletter?

Please contact: [info@eas-fhsc.org](mailto:info@eas-fhsc.org) || [coordinator@eas-fhsc.org](mailto:coordinator@eas-fhsc.org)

## FH Europe Annual Network Virtual Meeting 2020



**FH Europe**

The European FH Patient Network

FH Europe Annual Meeting 2020 is the highlight on the Agenda of the European FH Patient Network. Since its creation, leaders of the respective patient organisations have been gathering face to face to share, exchange and network.

In 2020, in collaboration with DIAGNOZA FH and Czech Society for Atherosclerosis, the Meeting was planned to take place in Prague but moved to virtual due to COVID19.

The closed sessions took place on Saturday 7<sup>th</sup> November, which comprised plenary presentations, guest presentations and breakout discussions. The event was well received and well attended with 51 participants joining in the morning and 41 in the afternoon, and was translated into French and Italian. The virtual format allowed some of the longstanding members to actively participate in discussions for the first time, as travel and language barriers were eliminated.

The opening session introduced the new Trustees of the Board, followed by breakout sessions. Guest speakers Nataša Jan (Slovenian Heart Foundation), Lucie Votavová and Tatjana Aleksicova (ScrenPro FH), and Zsofia Bakonyi (EFPIA Patient Think Tank) shared information about their organisations.

This virtual format also offers benefits of opening the Annual Meeting together with latest updates and education to a wider international audience.

### Next up:

- **18<sup>th</sup> Nov** – “Global FH Registry: A collaborative approach to better understand your inherited condition.” with Dr. Vallejo-Vaz, Dr. Lyons & Mr. Stevens.
- **2<sup>nd</sup> Dec** – Latest updates from EAS Leadership on Treatment & Novel Therapies in Genetic Dyslipidemias, ESC / EAS Guidelines, & Lipid Clinic Project.
- **16<sup>th</sup> Dec** – Final topic to be confirmed.

Register at <http://bit.ly/FHEuropeWebinar>

Moving on, FH Europe will scale up its awareness, education and advocacy activities with the use of social media and technology to reach and engage the general public about the inherited lipid conditions. **Please share FH Europe’s activities and presence with your patients on Facebook, Twitter, Instagram and LinkedIn.**

By FH Europe CE Magdalena Daccord

