

EAS FHSC NEWSLETTER

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In this Issue:

FHSC Global Registry Updates

FHSC Steering Committee Meeting 2019

FHSC Upcoming Events

FH Europe and FHSC Meeting

FHSC National Lead Investigators' Reports

EAS Interviews

FH Public Engagement

FH Studies Collaboration

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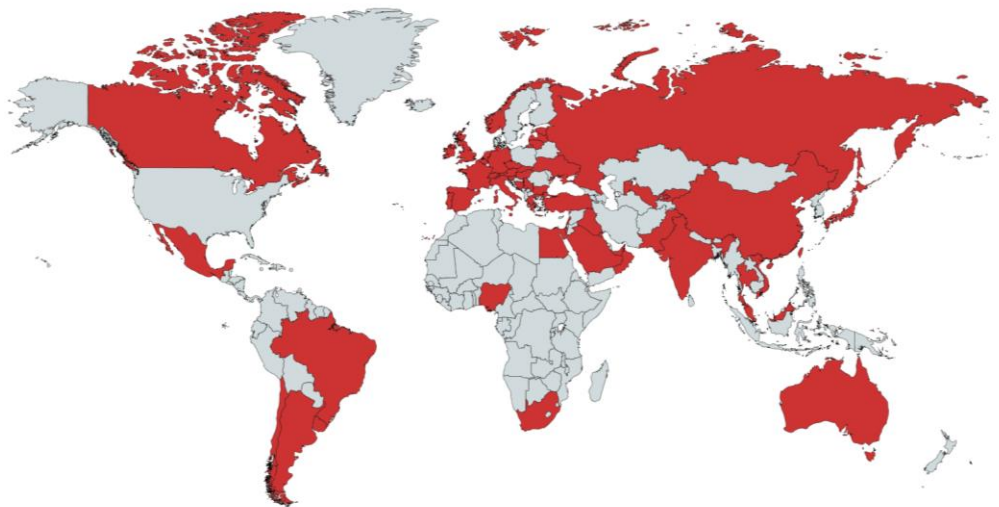
EAS FHSC Global Registry Updates

Headlines

The EAS FHSC Global Registry now contains over 61,000 cases with thanks to FHSC Investigators across nearly 60 countries (see shaded map below) sharing their FH data from their local independent registries with the FHSC.

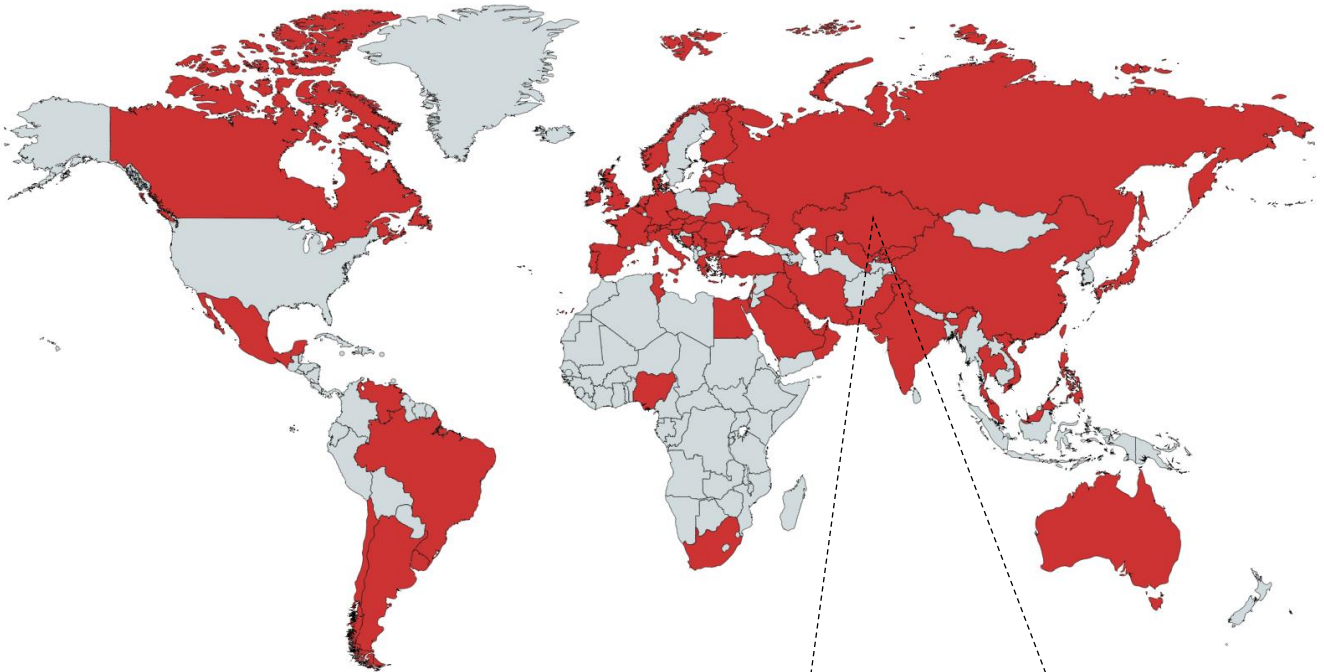
The FHSC are cleaning and performing statistical analyses of such data in preparation for a manuscript to be submitted to a high-impact medical journal this year.

NUMBER OF CASES
61,233

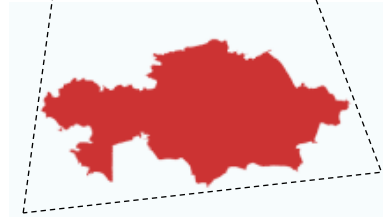


The number of cases recorded in the FHSC Global Registry will of course increase over time as more data is shared and the EAS FHSC International Network continues to expand.

FHSC Geographical Spread



The EAS FHSC currently encompasses 87 National Lead Investigators (NLI) spanning 69 countries as illustrated in the shaded map above. The current list of EAS FHSC Lead Investigators can be accessed [here](#).



The EAS FHSC Coordinating Centre at Imperial College London, UK is supporting the expansion of this Global Network of Lead Investigators to include more nations and promote the development of a comprehensive FH Global Registry. More information is available on the EAS FHSC [website](#).

The EAS FHSC welcomes Prof. Kairat Davletov of Kazakh National University as the FHSC NLI for Kazakhstan. Davletov's research interest is broadly CVD epidemiology and prevention.

Cardiologists from Indonesia have too expressed their interest in the FHSC.

Interested in Joining the EAS FHSC?

Are you a researcher with an interest in FH and collect clinical and/or genetic data on this hereditary condition, and would be keen to contribute to the EAS FHSC Global Registry?

If so, more information can be found in the open-access publication of the FHSC Study Protocol ([click here](#)) and the EAS FHSC Coordinating Centre would like to hear from you.

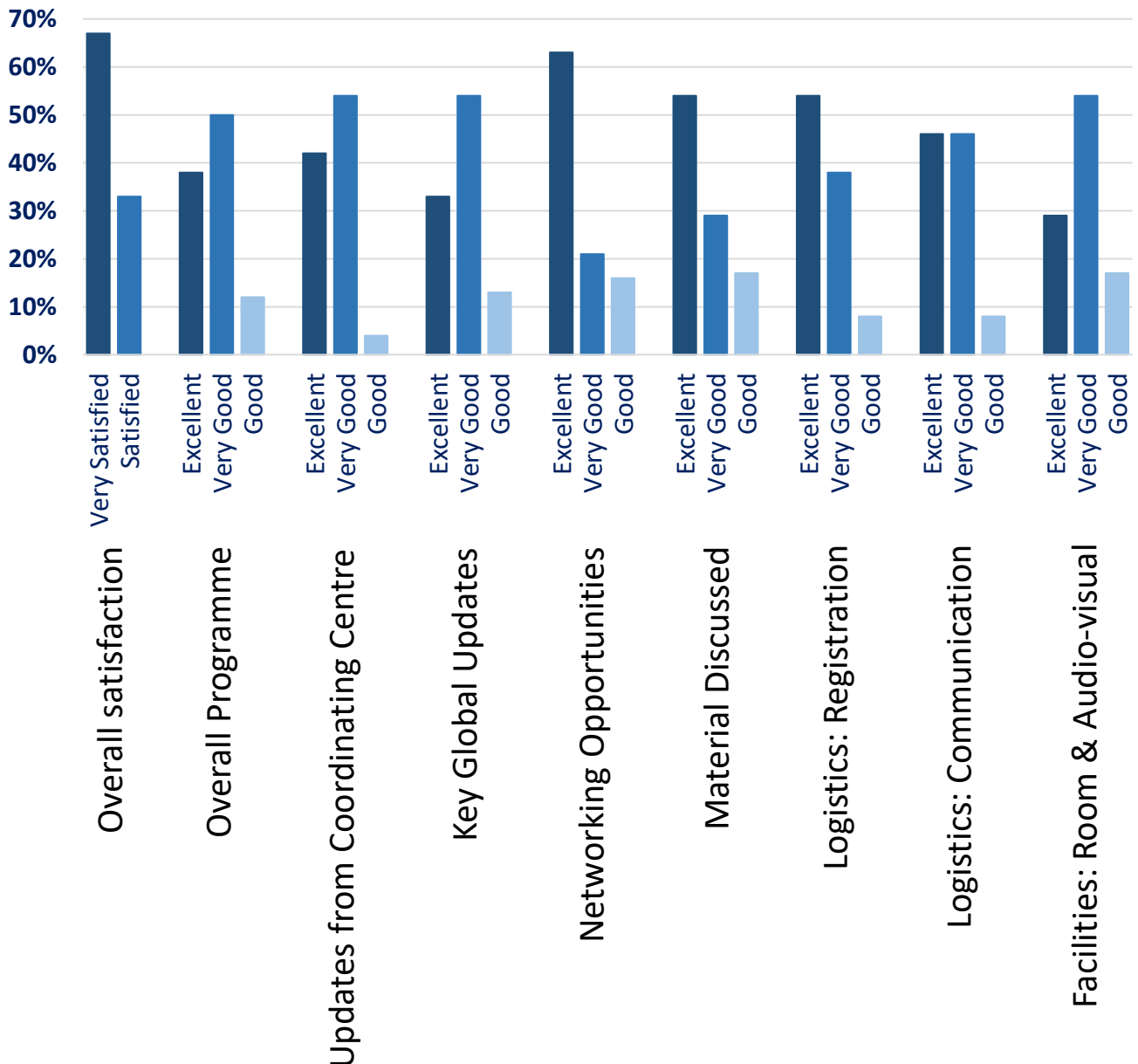
For enquires and discussions, contact the FHSC Coordinating Centre via info@eas-fhsc.org

Feedback from Attendees

The FHSC Steering Committee closed meeting, in conjunction with the EAS Congress 2019, was well attended by FHSC National Lead Investigators and Collaborators, and invited representatives of industry and the patient-focused network FH Europe.

The attendees were invited to complete an online survey to rate the different aspects of this meeting from 'Excellent', 'Very Good', 'Good', 'Poor' to 'Very Poor'. Twenty-four attendees completed the Survey. All ratings ranged from Good to Excellent.

The results of this survey below show that the FHSC Steering Committee meeting was well received. This valuable feedback provided by the investigators who replied to the survey will help to improve the next annual FHSC meeting.



FHSC Steering Committee Meeting

**FOR THE ATTENTION OF
The FHSC Steering Committee Members**

The EAS FHSC Steering Committee annual closed meeting of 2020 will take place in conjunction with the EAS 2020 Congress (31st May – 3rd June) in Geneva, Switzerland
on

Sunday 31st May 2020, from 09:00 to 14:00 hrs

This closed meeting is facilitated by the EAS FHSC Coordinating Centre and welcomes, **by strict invitation only**, EAS FHSC Steering Committee members and invited participants.

The agenda includes updates on the FH registry and associated projects from the FHSC Coordinating Centre of Imperial College London, UK and a series of presentations from invited speakers yet to be confirmed.



One voice in Europe on FH

FH Europe (<https://fheurope.org/>) is the European FH Patient Network which actively works together to secure early identification and diagnosis of FH patients to prevent early cardiovascular disease.



FH Europe

The European FH Patient Network

EAS FHSC and FH Europe announced partnership in March 2019 to speak with one voice on FH.

Through this collaboration, by linking FH patient groups with expert clinicians worldwide, globally established best practices will be shared, resulting in earlier diagnosis and a smoother pathway from patient referral to potentially life-saving treatment.

The EAS FHSC and FH Europe had a joint meeting at the EAS Congress 2019 to share ideas and formulate strategies to initiate their common goals to tackle the global burden of FH.

The photo below captured some of the participants in this meeting who contributed with much interest by sharing material and knowledge, and creating a global network accessible in multiple languages. The participants had the opportunity to discuss current initiatives in their own countries and globally.



Some of the key discussions that took place included:

- Diagnosis opportunities and strategies.
- Determining when and how to best screen for FH.
- Moving from treatment to prevention.
- Identifying the main challenges, which included:
 - Lack of awareness.
 - FH severely underdiagnosed.
 - No perception of urgency.
 - Need for a lot of commitment.
- Enlarging the scope to open to share with other countries.
- Need of local modifications of FH materials to adapt to the particularities of country/society/cultural matters.

The work of FH Europe was well received by the participants

Thailand FH Registry: A Success Story

Thai FH Registry was started in August 2018 after we officially joined the EAS-FHSC. Our national lead investigator is Dr. Weerapan Khovidhunkit, whereas the main coordinator is Dr. Poranee Ganokroj. The initial administrative site is at King Chulalongkorn Memorial Hospital in Bangkok. We opened the Facebook page called "ThaiFHNetwork" to increase awareness and received more than 2,600 likes so far.

We are now completing our first phase of our project by screening personnel at Chulalongkorn University and the Thai Red Cross Society.

Our second phase of expanding the registry to other sites all over the country has been met with interest and enthusiasm. Special Thanks to Prof. Kausik Ray, Dr. Brian Tomlinson, Dr. Antonio Vallejo-Vaz and everyone at EAS-FHSC and Thai FH Network to make it happen! We'll keep you posted!

By Weerapan Khovidhunkit



Iraqi Lipid Clinics Network: A Success Story

I started the establishment of the first lipid clinic in Iraq on 1st April 2015 after returning from Muscat where I was enrolled in the first lipid course in the MENA region organized by IAS and OSLA. At that time, one-third of Iraq was occupied by terrorists, so talking about delivering a lipid clinic project was madness! Most of the government budget had gone to supporting the army defending the country and my colleagues were not convinced, but this did not deter me!

After 18 months of struggling, I established the first lipid clinic in Iraq in Al-Diwaniya, 180 km South of the Capital Baghdad, on 15th February 2017! This success was celebrated by my colleagues in ISA and OSLA, which inspired me to expand the project to include further regions in Iraq and today we have twelve lipid clinics from North to South, including the Kurdistan territory. Al-Mamorah Scientific Bureau in Iraq kindly supported the cost of my travel to distant areas, which is neither easy nor safe, to convince the health authorities to establish local lipid clinics. I was then invited to speak about FH and propose strategies to tackle FH to the Iraqi Ministry of Health.

Such strategies and developments included:

- Official launch of the National Paediatric FH Screening Program in MENA region, which is now active in three Iraqi Cities and still expanding.
- Implementation of the Premarital FH Screening Program in Iraq due to the high rate of consanguinity.
- Implementation of the FH Ambassador Mission, where I travel to countries where Iraqi residents are located to talk to them about FH. For example, I recently delivered lectures in Arabic to Iraqis in Cairo, Los Angeles.
- Implementation of a mass awareness program for teachers in primary schools, civil society organizations, general practitioners and specialists in hospitals, and medical students and the public via broadcasting TV, Radio and Social Media.
- Establishment of the Doctor –FH Patients' Group via social media to discuss FH including risk factors, need for check-ups, side effects of medications, etc! The aim is to offer free medical consultations for FH patients for life!
- Launch of the Arabic website for disseminating knowledge among patients and health care professions www.iraqilcn.com.

I thank my colleagues in IAS and OSLA, and Al-Mamorah Scientific Bureau and the FH Network who supported me to achieve this vision.

I currently supervise the Iraqi FH project from Cairo, Egypt.

By Mutaz Al-Khnifawi, President of ILCN



Interviews at EAS Congress 2019



Professor Kosh Ray (Imperial College London, UK), Lead on FHSC, discusses the importance of early diagnosis of familial hypercholesterolemia.

<https://www.eas-society.org/news/453207/News-and-views-from-EAS-2019-Maastricht-Video-interview-from-Late-breaking-session-Tuesday.htm>



Dr Antonio J. Vallejo-Vaz (Imperial College London, UK), FHSC Coordinating Centre Investigator, discusses the EAS FH Studies Collaboration Registry.

<https://www.eas-society.org/news/453195/News-and-views-from-EAS-2019-Maastricht-Video-interview-about-EAS-FH-Studies-Collaboration-Registry.htm>



Professor Derick Raal (University of the Witwatersrand, Johannesburg, South Africa), FHSC Executive Committee member and National Lead Investigator for South Africa, discusses FIND FH.

<https://www.eas-society.org/news/453639/News-and-views-from-EAS-2019-Maastricht-Video-interview-from-Science-at-a-Glance-Find-FH.htm>



Professor Winfried März (University of Heidelberg, Germany and University of Graz, Austria), FHSC National Lead Investigator for Germany, discusses the CaReHigh FH Registry in Germany.

<https://www.eas-society.org/news/455587/News-and-views-on-FH-from-EAS-2019-Maastricht-Video-interview-on-the-CaReHigh-FH-Registry.htm>



Dr Meral Kayikcioglu (Ege University, İzmir, Turkey), National Lead Investigator for Turkey, discusses FH initiatives in Turkey.

<https://www.eas-society.org/news/455592/News-and-views-on-FH-from-EAS-2019-Maastricht-Video-interview-on-FH-initiatives-in-Turkey.htm>



Professor Maciej Banach (Medical University of Lodz, Lodz, Poland), FHSC National Lead Investigator for Poland, discusses the status of FH care in Poland.

<https://www.eas-society.org/news/455593/News-and-views-on-FH-from-EAS-2019-Maastricht-Video-interview-on-the-status-of-FH-care-in-Poland.htm>

Imperial Festival 2019

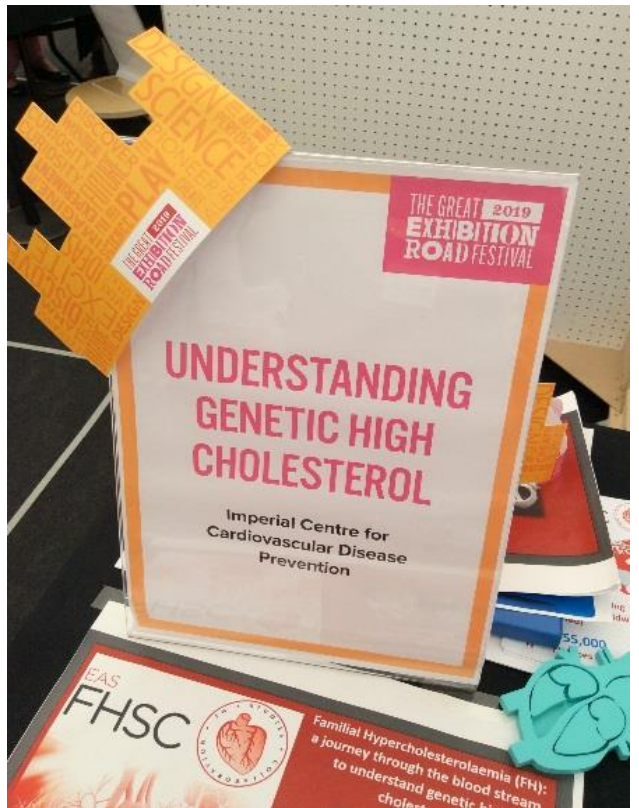
The FHSC Coordinating Centre Investigators had a presence in the 'Mind and Body' tent at the annual Festival hosted and organised by Imperial College London at South Kensington Campus. This was a free-to-attend public engagement event whereby Imperial gave back to the local community. Thousands of visitors attended with their families and participated in the fun activities that weekend.

THE GREAT 2019 EXHIBITION ROAD FESTIVAL

 #ExRdFest



The FH booth had fun activities for children including 3D puzzles modelling the heart and graphical illustrations of the cardiovascular system via printouts. Also there was a computer-coded t-shirt print to show an e-model of the heart for education.



Many adults visited the booth to improve their awareness of the burden of FH and its risk factors. This event was well attended and received.

