

EAS FHSC NEWSLETTER

Issue 13, July 2020

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The Latest

EAS FHSC Steering Committee Annual Closed Meeting

Sunday 4th October 2020, from 09:00 to 13:00 hrs

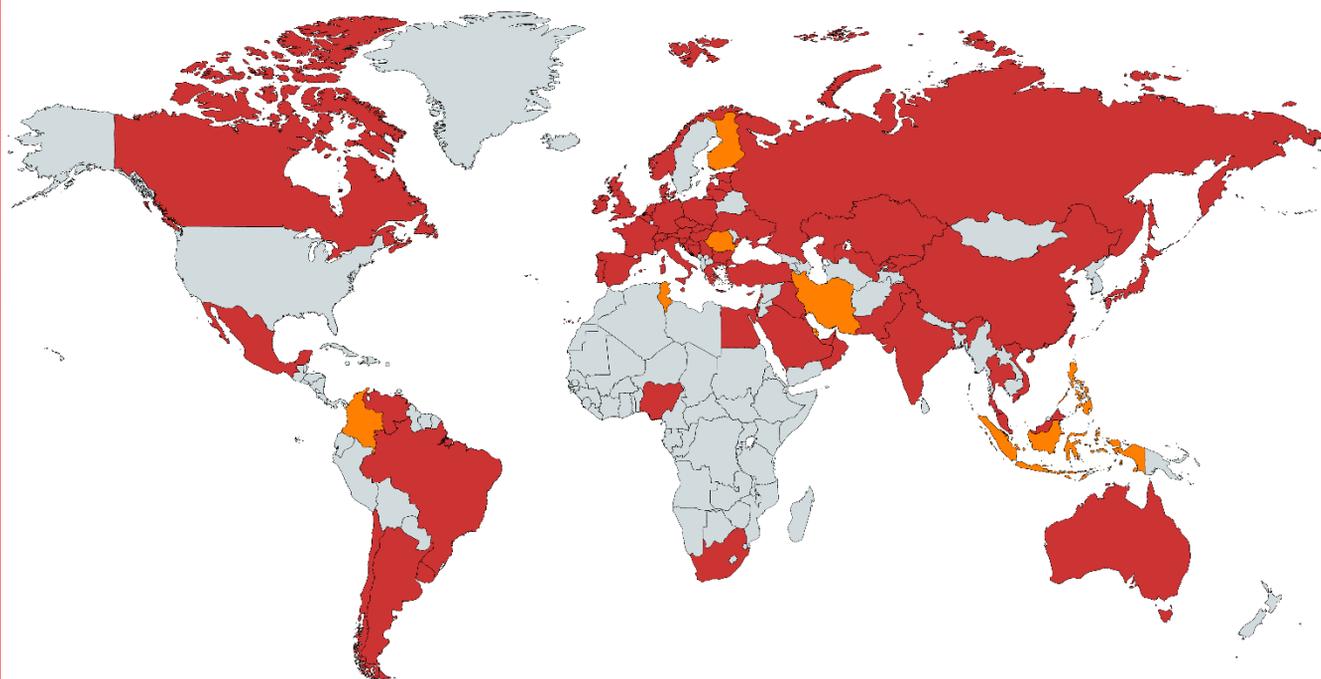
The Agenda remains unchanged
Attendance to this meeting is strictly by invitation only

In conjunction with the 88th EAS Congress
4th - 7th October 2020



EAS FHSC Global Network and Registry

90 Lead Investigators, with the National Lead Investigators (NLI) listed [here](#), spanning **71 countries** of which 62 have contributed data (red) and data is expected from the 9 others (orange) in the network as shown in the shaded map below.



Approximately 62.5K FH Cases Registered Across 62 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](#))?

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

Contact info@eas-fhsc.org for enquires and discussions

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: **FHSC Individual Data Entry Application (IDEAP)**.

FH Education and Research in Taiwan



Taiwan Society of Lipids and Atherosclerosis (TSLA) hosted the 12th conference of the Asian Pacific Society of Atherosclerosis and Vascular Diseases (APSAVD) in Taipei, Taiwan on 20th - 22nd September 2019 for the second time since 1998.

This conference was well attended with approximately 1,300 researchers, medical doctors and students from more than 20 countries keen to participate and present their academic papers.

There were three FH sessions providing educational activities, academic exchanges and discussions, from prevalence to management of FH, including:

- (1) IAS, JAS and APSAVD Joint Session: Asian Perspective of ASCVD.
- (2) FH in Asia-Pacific Regions.
- (3) Educational Seminar: Management of FH.



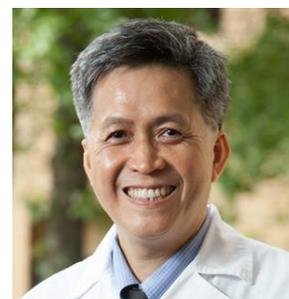
In 2018 and 2019 we published two papers on the diagnosis¹ and psychosocial aspects² of FH under the call for a special issue for FH research.

The 2018 paper¹ reports the first capture-based next-generation sequencing (NGS) testing for FH to cover the whole LDLR genomic region, and therefore making reliable structural variation detection in FH. We also identified LDLR c.1186+2T>G as a novel and common disease-causing variant using capture-based NGS screening in ethnic Chinese in Taiwan. This panel can comprehensively detect disease-causing variants in LDLR, APOB, and PCSK9 for FH patients.

The 2019 paper² reports novel findings of increased depression perception in FH patients compared with those of normal lipid levels and patients with hypertriglyceridemia.

1. Hsiung YC, Lin PC, Chen CS, Tung YC, Yang WS, Chen PL, Su TC. Identification of a novel LDLR disease-causing variant using capture-based next-generation sequencing screening of familial hypercholesterolemia patients in Taiwan. *Atherosclerosis* 2018; 277:440-447.

2. Chang NT, Su TC. Investigating the association between familial hypercholesterolemia and perceived depression. *Atherosclerosis Supplements*. 2019; 36: 31-36.



By Dr. Ta-Chen Su,
FHSC NLI of Taiwan

Official launch of the first FH advocacy group in Iraq



It was not possible for patients in Iraq to play a role in decision making concerning FH, a disease they suffer from, since the decisions was exclusively made by physicians.

During the FH Foundation's 'Global Call to Action' meeting in Atlanta, US in October 2019, we were asked to pay more attention to this point in our respective countries.

This initiative was never discussed before in our local health authorities in Iraq, so I therefore developed this initiative on a local level by educating patients on the importance of their role in decision making. Patients were gathered via social media to form a group named 'My Friends'.

For six months we discussed everything regarding lack of drugs and the side effects, the level of negotiations between our network and MOH in Iraq, our efforts in this field, and members of the group were sharing their experiences with FH. This initiative was well received by My Friends.

We have since established a FH patient advocacy group in Iraq and recruited our first patient representative, a HoFH patient in their final year of study. The FH advocacy group had the inaugural virtual meeting on 22nd May 2020.

By Dr. Mutaz Alkhnifsawi, FHSC NLI of Iraq



Expertise & diversity: Critical elements to fulfilling the FH Network's purpose

FH Europe appointed five new members to its Board of Trustees. This Board represents the understanding and voices of different stakeholders in a wider healthcare ecosystem, from patients to patient organisations' leaders, FH clinicians and researchers, healthcare policy makers, industry consultants, topic matter experts, innovators, and entrepreneurs.

Among them they represent eight nationalities and speak English, Italian, Swedish, Romanian, Polish, Latvian, French and German. All of this while simultaneously reaching gender parity on the leadership team:

- Samuel Gidding, a preventative paediatric cardiologist, is a world class FH expert and a senior author of the Global Call to Action on FH.
- Joanna Taylor is a partner with Ernst & Young AG (EY) with a focus on Health Sciences and Wellness, and a published researcher on social media narratives in non-communicable diseases (NCDs).



- Marius Geantă, is President and Co-Founder of the Center for Innovation in Medicine, a non-governmental organisation, focused on innovation in the healthcare sector.
- Dorota Zgódk, Head of Outreach and Partnerships in Rare Diseases at CheckOrphan, brings life sciences experience in biopharma industry, strategic and management consulting, and research and science.
- Giovanni Nisato one of the co-founders the Health Hacking Lab, a non-profit for patients, caregivers and innovators to co-create solutions that address everyday health challenges.

This diverse Board with a wide range of skills, experience and perspectives will bolster the FH Europe Network resilience and give it the best chance of fulfilling its purposes into the future.

For more information about [FH Europe](#) please contact Chief Executive, Magdalena Daccord md@fheurope.org.

Also check out our, [JustGo](#) international 'Patient to Patient' campaign, which has been developed by the FH Europe and the [Global Heart Hub](#), both of which are non-profit organisations providing platforms for those affected by cardiovascular disease (patients & carers).

When Your Heart Says So...



Publication: An FH Article

Pengwei Hu, Kanika I. Dharmayat, Christophe A.T. Stevens, Mansour T.A. Sharabiani, Rebecca S. Jones, Gerald F. Watts, Jacques Genest, Kausik K. Ray and Antonio J. Vallejo-Vaz have published an [article](#) in *Circulation* (Vol 141, Issue 22, June 2020, Pages 1742-59) entitled:

Prevalence of Familial Hypercholesterolemia Among the General Population and Patients With Atherosclerotic Cardiovascular Disease

A Systematic Review and Meta-Analysis

Authors conducted a meta-analysis on 62 studies involving over 7.3 million individuals which showed that FH is among the most common genetic diseases in the general population and across different world regions.

This study shows that FH is a prevalent genetic disorder among the general population, affecting approximately 1 in 311 individuals overall. The prevalence among individuals with established cardiovascular disease was 18-fold higher (1 in 17) than in the general population.

The results support the advocacy for the institution of public health policies, including screening programs, to identify FH early, treat early, and prevent its global burden.

Learn more about the worldwide burden of FH by reading this [article](#).