

EAS FHSC NEWSLETTER

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EAS FHSC Global Registry Updates

- The FHSC Global Registry now has **61,666 cases** recorded across 60 countries.
- FHSC Data Entry and Harmonisation Web-based Platform Version II has been developed by the Coordinating Centre and is currently being tested externally by numerous National Lead Investigators.
- FHSC network spans 69 countries as shown in the **shaded** map below and includes 88 Lead Investigators with the NLI's listed [here](#).



Become part of the EAS FHSC

Are you a researcher with an interest in FH, collect clinical and/or genetic FH data and 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

FH Studies Collaboration

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Follow us at:

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



The European FH Patient Network shifts to the next gear

Following on the mission to improving and saving lives of patients and their families impacted by FH and other forms of dyslipidaemia, FH Europe created a new role of Chief Executive and appointed Magdalena Daccord in Nov 2019. After confirming a critical partnership with EAS FH SC and successfully launching a collaborative Global Call to Action on FH, the Network is looking at Magdalena to carry the organization to the next phase.



"We have developed FH Europe and worked to support the European FH patient network and become one powerful voice in Europe on FH, together with EAS FHSC. Magdalena has the right experience to move FH Europe to the next level, to deliver our strategy and beyond."

- Jules Payne, Chair of the Board of Trustees.

Magdalena brings a strong cross functional healthcare experience from the non-profit organizations in drug development, patient advocacy and pharmaceutical industry.

"I am delighted to be joining FH Europe. It has been very successful in raising awareness of FH in Europe, building strong collaborations with local patient organizations and other key stakeholders locally, internationally and globally. I look forward to consolidating and building on these partnerships as well as embracing the exciting opportunities made possible by new treatments being developed for patients with FH. My aim is to work together to secure early identification and diagnosis of FH patients to improve and save lives."

- Magdalena Daccord, Chief Executive.

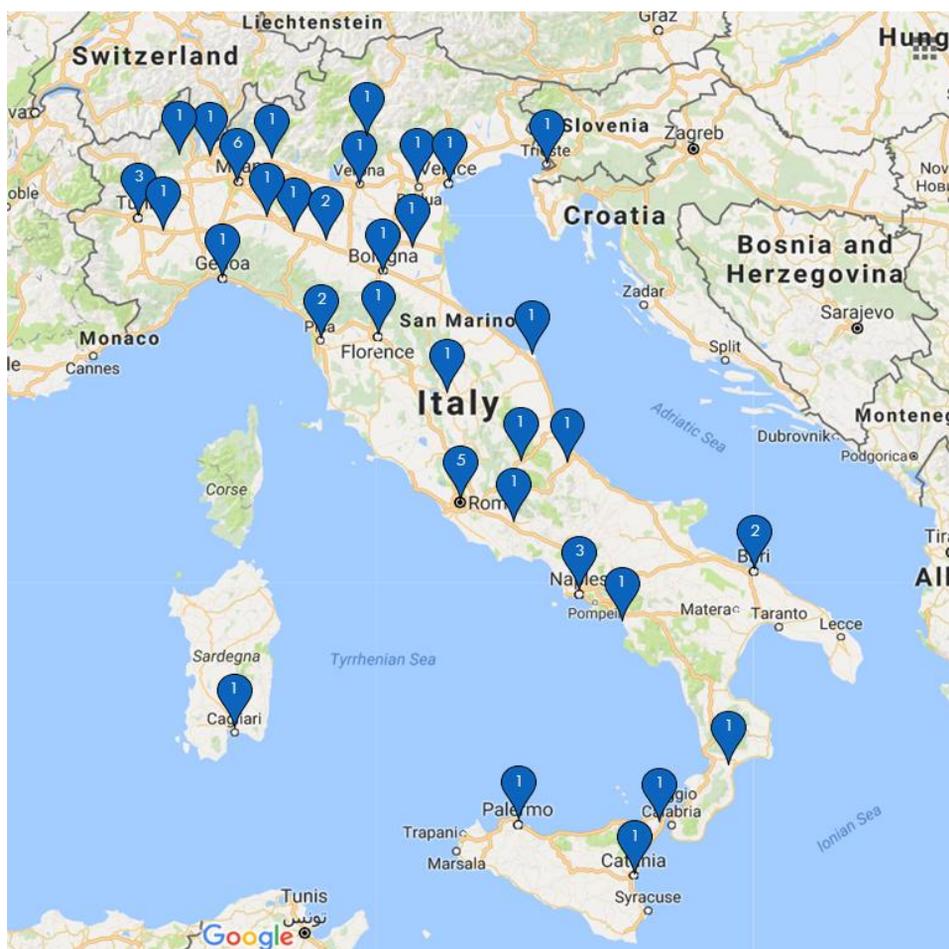
Next immediate actions for the new Chief Executive are meeting with the national patient organisations within the Network and engaging with the scientific partners as well as sponsors in the CVD/FH space.

Characterization of Italian Patients with FH: The LIPIGEN Study 

LIPIGEN (Lipid TransPort Disorders Italian GENetic Network) is an observational, multicenter, retrospective and prospective study aimed to create a national database of Italian FH patients (see figure below) and to improve the identification and management of patients affected by genetic dyslipidemias, including FH. Data collected included personal and family medical history of hypercholesterolemia and cardiovascular and cerebrovascular events, clinic signs, and lipid levels. These data allow the application of the Dutch score Lipid Clinic Network (DCLN) for the clinical diagnosis of FH. If DCLN score is ≥ 6 , then genetic analysis is recommended.

To date, the LIPIGEN study included 49 lipid clinics and accounted for more than 8,300 patients (1500 subjects <18 years at diagnosis) with a clinical and/or genetic diagnosis of FH. The mean age at diagnosis was 31.5 ± 18.6 years. Among the patients with genetic testing (about 80%), 72% had a positive genetic diagnosis of FH, mainly for pathogenic variants on *LDLR* gene; among them, 63 patients were homozygous for variants on *LDLR* gene and four patients were homozygous for variants on *LDLRAP1* gene.

By Professor Alberico Catapano, NLI Italy



Veronica Zampoleri, Marta Gazzotti, Manuela Casula on behalf of the LIPIGEN Group; Marcello Arca, Maurizio Averna, Stefano Bertolini, Sebastiano Calandra, Alberico Luigi Catapano, Patrizia Tarugi (LIPIGEN Steering Committee)

Some Activities of the Vietnam FH Team



Since the press conference of “FH in Vietnam children” on November 14, 2018, we have continued to screen children and parents for FH among family members of people with known FH. We have given them lipid-lowering treatments and educated how hypercholesterolemia management could have considerable impact in preventing the medical consequences of this disorder in two generations simultaneously.



On September 28, 2019, a young Resident of Cardiology scored high in his Master's Thesis defence on the topic 'FH in Premature Coronary Artery Disease (PCAD) in Viet Nam'.

The Viet Nam FH Lead and student in Viet Nam to Hanoi Medical University .



We are going to publish an article on November 2019 in the *Journal of Vietnamese Cardiology* (ISSN 1859-2848) entitled:

“Plasma exchange therapy for a patient with homozygous familial hypercholesterolemia in Viet Nam”

By Dr Truong Thanh Huong , NLI Vietnam



Updates from Singapore

FH Case identification, Assessment, Reduction in adverse Events (FHCARE) was started in June 2015 led by Assoc. Prof. Tavintharan Subramaniam, Prof. Tai E Shyong and Prof. Terrance Chua Siang Jin. FHCARE is a collaboration between cardiologists, and adult and paediatric endocrinologists across 11 public institutions focusing on a joint effort to increase awareness, coordinate care and research for FH. Given an estimated prevalence of 1 in 250, about 22,000 people are estimated to have FH in Singapore, but the actual number is unknown. The goal of FHCARE is to identify these patients and family members early to reduce the morbidity and mortality associated with this condition through appropriate treatment.

Currently, the team has obtained research grants from Alexandra Health Endowment Fund and Singapore Heart Foundation (SHF) to study FH.



Dr. Sanjaya Dissanayake, Assoc. Prof. Tavintharan Subramaniam, Dr. Sharon Pek Li Ting on behalf of the FHCARE team.



The team hopes to develop a centralized national FH registry in the near future. The FHCARE team collaborates with SHF on FH awareness week/World Heart Day to help raise FH awareness to the public annually.



An FH website was launched recently to help disseminate knowledge among clinicians and general public www.myheart.org.sg/FH. Patient videos, posters and pamphlets have been developed and made publicly available through this website.

This year, the team won the prestigious National Healthcare Group awards 2019 for Outstanding Research Impact Award. This award is given as recognition for FHCARE, where the programme demonstrated translational impact to healthcare provision nationally. This award was presented by Prof. Lim Tock Han, Deputy Group Chief Executive Officer (Education and Research), National Healthcare Group.

By Assoc. Prof. Tavintharan Subramaniam, NLI Singapore

FHSC Steering Committee

FOR THE ATTENTION OF
FHSC Steering Committee Members

*****Invitations and agenda will be sent soon*****

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.



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If you are interested in contributing to the next issues of the EAS FHSC Newsletters with any text, publication, events, etc. please contact us at:

coordinator@eas-fhsc.org or info@eas-fhsc.org

