

EAS FHSC NEWSLETTER

Issue 12, April 2020

Issue 12

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EAS Congress
Postponed

The Latest

FHSC National Lead
Investigators' Reports

Partnership with EAS
FHSC and FH Europe

EAS Congress Postponed to October 2020

EAS FHSC Steering Committee Annual Closed Meeting

NEW DATE

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

&

FHSC Dinner on Saturday 3rd October 2020

The Agenda remains unchanged

Attendance to this meeting is strictly by invitation only

In conjunction with the 88th EAS Congress in Geneva, Switzerland
4th - 7th October 2020



@DENISABBONATOPHOTOGRAPHY

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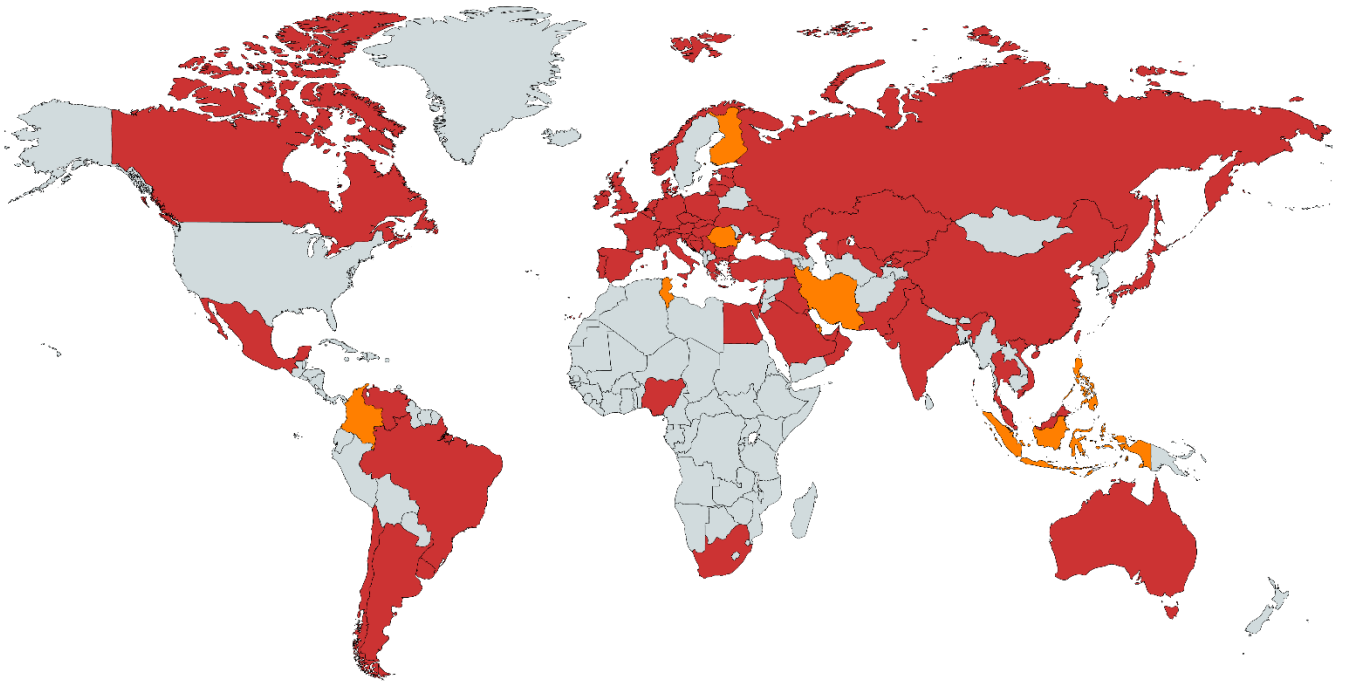
[#fhscglobalregistry](https://www.facebook.com/fhscglobalregistry)



www.eas-society.org/fhsc

EAS FHSC Global Network and Registry

90 Lead Investigators, with the National Lead Investigators (NLI) listed [here](#), spanning **71 countries** as shown in the map below shaded in **red** (contributed data to FHSC) and **orange**.



>62K FH Cases Registered Across 62 Countries (Shaded Red)

The EAS FHSC welcomes:

- Indonesia onto the map, led by new NLI Dr. Bambang Dwiputra
- Columbia onto the map, led by new NLI Dr. Rafael Campo
- New NLI of Finland Dr. Saara Mesto
- New Lead Investigator of Venezuela Dr. Marcos Miguel Lima-Martinez

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?

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'](#)

EAS FHSC Registered on ClinicalTrials.gov

The EAS FHSC Global Registry is now registered as an observational study (Identifier: NCT04272697) on the US National Library of Medicine's '[ClinicalTrials.gov](https://clinicaltrials.gov)' public-facing website, to increase public awareness of the project, ethical compliance (though registration is not mandatory for observational studies) and transparency.

FHSC IDEAP II and Webinars facilitated by the FHSC Coordinating Centre

FHSC Individual Data Entry Application Version II (IDEAP II), exclusive to FHSC Investigators and their local teams, is now in use! Advancements support new functionalities essential to entering and managing local-level data, and sharing data with the FHSC Global Registry.

- Provides a cost-free database for National Lead Investigators (NLIs) to set up their own registries under unique local registry names.
- Enables NLIs' local collaborators to register as 'users' for patient data entry within their national registries, either on behalf of their respective NLI or as a separate local site/centre.

With thanks to the FHSC testers of IDEAP II for providing their helpful suggestions.

IDEAP II Webinar Series was provided to new and existing 'users' to give guidance on the use of this sophisticated web-based platform. These tutorials were well received.

Further Webinar Series would be available upon demand if FHSC Investigators, yet to participate, and/or their local collaborators requires a tutorial on the use of IDEAP II as a 'user'.

FHSC Investigators may contact the FHSC Coordinating Centre to make a request for a Webinar via email info@eas-fhsc.org

FHSC Data Entry Application Implemented in HELLAS-FH



Hellenic Familial Hypercholesterolemia (HELLAS-FH) Registry established in March 2016 by the Hellenic Atherosclerosis Society (HAS) is a national, multi-centre initiative to monitor FH patients in Greece.

Specialised lipid clinics ($n=20$) in Greece were invited to participate. Registry data were being collected through a secure online portal. By June 2019, approximately 2,000 patients had enrolled (Figure 1).

However, our online data collection system had shortfalls, such as:

- Monthly maintenance costs
- Limited customisation features
- Difficulty sharing data with the EAS FHSC

We were therefore excited to be given the opportunity to switch our database to the **FHSC Individual Data Entry Application (FHSC IDEAP)** to mitigate these shortfalls.

We started migrating databases from June 2019 and by early 2020 the upgraded version of IDEAP (FHSC IDEAP II) was freely-available. We thank the FHSC Coordinating

Centre and their Data Manager & Software Developer Christophe Stevens for their invaluable support.

Our experience so far with the cost-free FHSC IDEAP II is superb. The app is very well designed, highly customisable and user-friendly, and data extraction is straightforward and readily available for analysis. All data on our database were successfully transferred to this new system.

Every HELLAS-FH Principal Investigator (PI) from each local site may register as a user of FHSC IDEAP II and be assigned a unique username and password to sign in and upload patient data. Every PI has access to their site data, while the National Lead Investigator (NLI) has access to all sites' data to oversee the entire local registry.

We highly recommend to all FHSC NLIs to consider implementing the FHSC IDEAP II in their countries for ease of data entry and transfer.

By Dr. Chris Rizos and FHSC NLI of Greece Dr. Evangelos Liberopoulos, on behalf of the HELLAS-FH Investigators

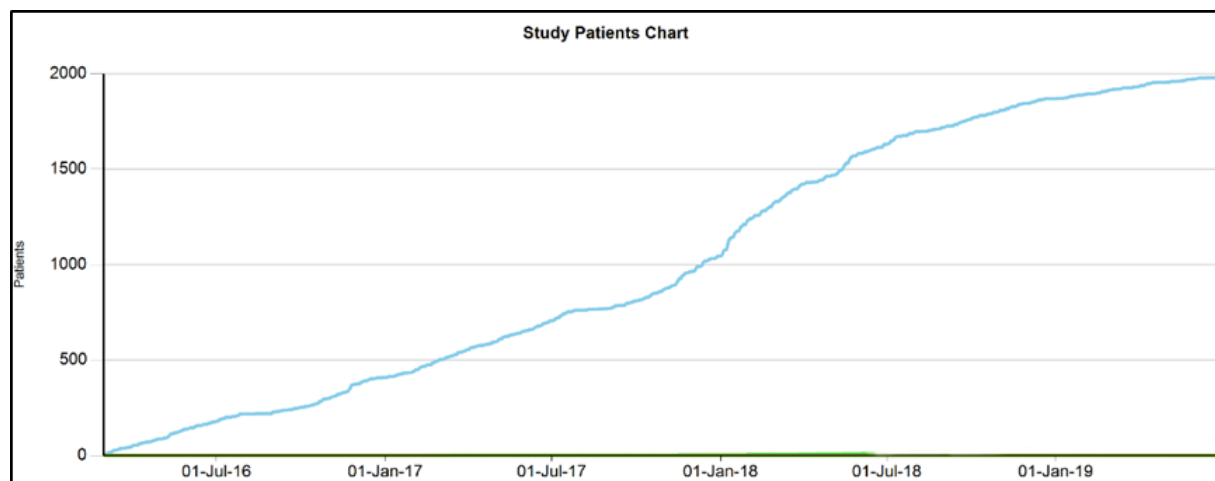


Figure 1. Number of patients enrolled in the HELLAS-FH registry by June 2019

FH Europe Community came Together to Connect, Exchange and Support

As the world has shifted dramatically in the last few weeks to respond to coronavirus (COVID-19), significant impact has been observed by FH patients' organisations (PO) in Europe. It varies from emotional to daily operational implications related to patients with FH and other dyslipidemias having access to doctor consultations, blood tests, treatment, etc.

FH Europe organised an 'All Network Virtual Connect' on 24th March to provide a platform for POs to connect, support and share during these times of isolation. National POs, across 14 countries, lead by patients or physicians participated together with non-affiliated patients.

POs shared similar concerns regarding:

- Limited access to information on COVID-19, and CVD and FH
- Misleading information on social media around treatment with statins and PCSK9 inhibitors

- Limited access to specialists, extended apheresis intervals and blood tests

POs shared local-level solutions regarding:

- Telephone consultations
- Improved medicine delivery/collection systems
- Research available

This Virtual Connect call resulted in the creation of a 'Good Practices' document for POs during the COVID-19 crisis. The next Virtual Connect meeting will take place on 7th April to monitor the situation in these participating countries.

As FH Europe is committed to its mission of securing early identification and diagnosis of FH patients to prevent early cardiovascular disease, the charity is currently working on strengthening the organisation by recruiting Trustees of the Board and Advisors of a Scientific Committee.

For more information please contact Chief Executive, Magdalena Daccord, via email md@fheurope.org.

By FH Europe Chief Executive Magdalena Daccord

