

# EAS FHSC NEWSLETTER

Issue 08, May 2019

## Issue 08

## EAS FHSC Global Registry

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## Providing the Essential Resources

### FHSC Individual Data Entry Application

*Providing the essential resources to the FHSC Global Consortium*

The EAS FHSC Coordinating Centre based at Imperial College London is committed to continuously improving the data sharing and operational strategies for the benefit of this Global Consortium. The Coordinating Centre would like to remind and encourage the FHSC Lead Investigators to make use of this registry data software technology developed for the FHSC Network.



A great IDEA: Individual Data Entry Application is available to support the EAS FHSC Global Registry.

This sophisticated research data entry system has recently been developed by the FHSC Coordinator Centre to provide a user-friendly software platform to support the needs of the FHSC Lead Investigators to facilitate the FH Global Registry.

The unique features of IDEA, detailed in the previous Newsletter ([Issue 07, January 2019](#)), makes this secure platform beneficial to start a customised registry from scratch, enable case-by-case entry and promote standardisation, and easily manage and share data with the FHSC Global Registry Hub.

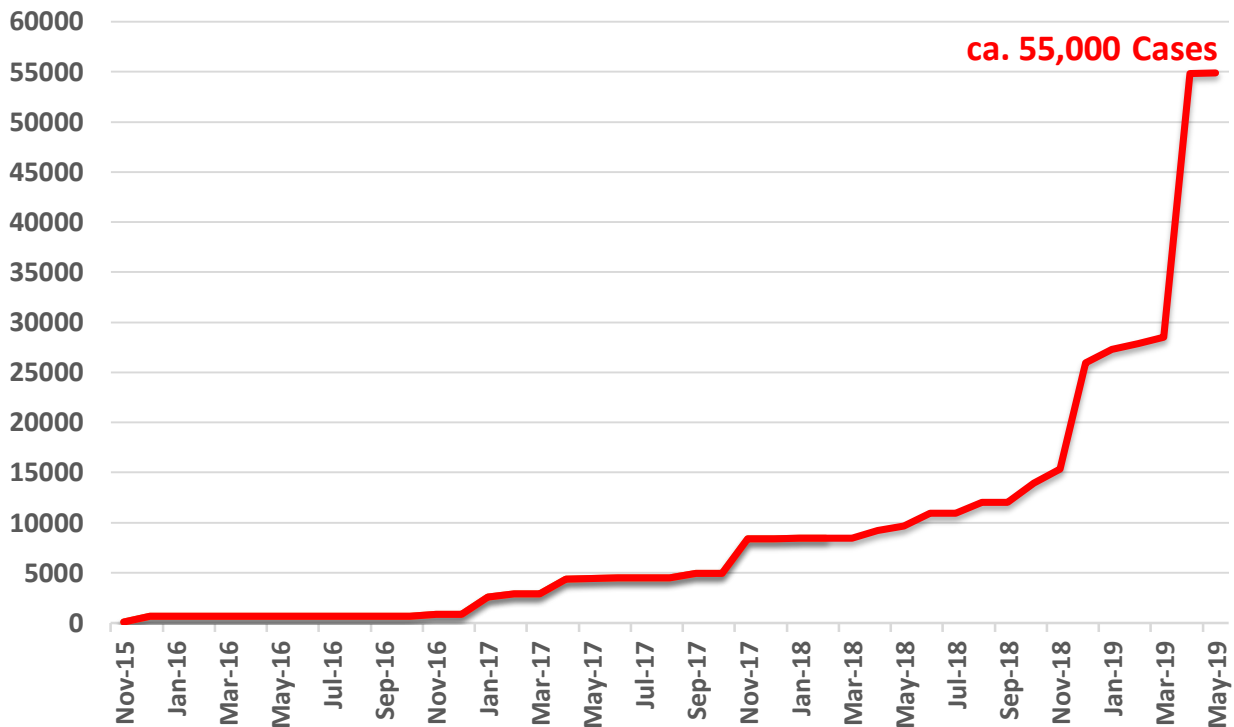


The use of IDEA is restricted to approved FHSC Investigators only, which they may access cost-free to develop their National Registry by signing into the FHSC Website ([www.easfhsc.org](http://www.easfhsc.org)).

Further information and support for the use of this innovative data capturing and management technology for the EAS FHSC Lead Investigators is available by contacting the EAS FHSC Coordinating Centre via email to [coordinator@eas-fhsc.org](mailto:coordinator@eas-fhsc.org)

## Success thus Far

### Number of Cases



This Figure Shows the cumulative number of cases (x axis) recorded in the EAS FHSC Global Registry to date (early May 2019).

The EAS FHSC Global Registry has recorded a total number of FH Cases approaching 55,000 to date and counting! The above figure shows a steep increase in the cumulative number of cases recorded in the FHSC Global Registry from January 2019 as more data have been shared, particularly the recent inclusion of 26,000 FH cases from the FHSC Investigators in the Netherlands has made a substantial contribution.

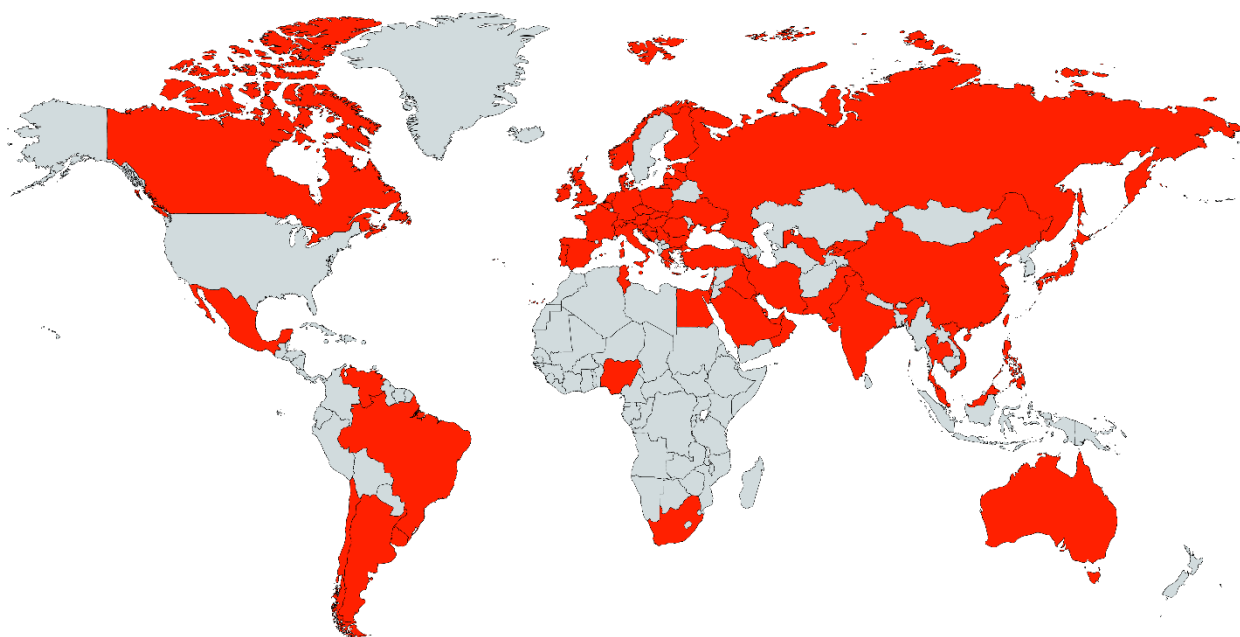
The number of cases recorded in the FHSC registry will of course increase over time as more data is shared and the EAS FHSC Global Network continues to expand.

The collaborative work of the EAS FHSC Investigators and Imperial College London's FHSC Coordinating Centre continues to ensure the success of this Global FH Registry to run long-term in order to include new individual cases, enable follow-up of existing cases and integrate new cohorts into the registry, and to account for contemporary changes in clinical practice so that the findings remain current and relevant.

### Publication Plan for 2019

This global FH large dataset will, for the first time, be subjected to statistical analyses by the EAS FHSC Coordinating Centre to generate results for a 2019 publication in a high-impact journal. In parallel, the FHSC are submitting a late breaking registry abstract to the ESC 2019 congress on behalf of the FHSC investigators.

## FHSC Global Network

**Geographical Spread**

The EAS FHSC currently encompasses 84 Lead Investigators spanning 68 countries as highlighted in the 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](#)

**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 share your anonymised data with the EAS FHSC? 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 EAS FHSC Coordinating Centre via [email](#)

## EAS FHSC and FH Europe Collaboration

**Announcement**

The EAS FHSC have teamed up with FH Europe to strengthen the global efforts to manage FH with the aims of improving health care on an international level. For more information [click here](#)

## FHSC Steering Committee Meeting

### SAVE THE DATE

**EAS FH Studies Collaboration Steering Committee Meeting**  
in conjunction with the EAS 2019 Congress in Maastricht, the Netherlands, May 26-29

The EAS FHSC Steering Committee annual meeting of 2019 will take place on the last day of the 87<sup>th</sup> EAS Annual Congress at the *MECC Convention Center, Maastricht, the Netherlands* on:

**Wednesday 29<sup>th</sup> May 2019, from 12:45 to ca. 22:00**

This meeting is facilitated by the EAS FHSC Coordinating Centre and welcomes, **by strict invitation only**, EAS FHSC Steering Committee members of this global FH clinical registry.

The agenda includes updates on the FH registry from the FHSC Coordinating Centre of Imperial College London and a series of presentations from invited speakers covering genetics in FH, public and patient involvement in FH, updates from the EAS, public health policies and strategies on FH.

## FHSC Exhibition Booth

### CHAT WITH US

**EAS FH Studies Collaboration booth**  
at the Exhibition of the EAS 2019 Congress in Maastricht, the Netherlands, May 26-29

Visit the EAS FHSC booth within the main EAS Stand (No. 8) in the Exhibition of the 87<sup>th</sup> EAS Congress and meet the FHSC team.

This booth serves as the FHSC base during the Congress and will be attended by members of the FHSC Coordinating Team.

This will be a useful forum for discussing matters, making suggestions and resolving queries with the FHSC Investigators, and practical demonstrations on the FHSC website and IDEA software, and advertising the project and meeting new colleagues.



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:  
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