

EAS FHSC NEWSLETTER

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Issue 05

*Special Issue on the
FHSC Steering
Committee Meeting,
Lisbon 2018*

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Meeting at a glance

On Tuesday 8th May 2018, the *FHSC Steering Committee Meeting* took place at the Centro de Congressos de Lisboa, immediately following the 86th EAS Congress.

The meeting was the annual gathering of all the FHSC National Lead Investigators, a closed event where updates on the development of the project were shared amongst participants. The attendance this year was of over 100 delegates, including NLI's, FHSC Coordinating team, Executive Committee members, industrial partners and representatives from patients organizations.

The meeting was very successful and overall positive feedbacks were received. Similarly to last year, the event represented an useful opportunity for networking and exchanging information amongst FH investigators, aspect that has been mostly valued by all participants. It served as a forum for updating colleagues on matters and initiative related to FH in different regions/countries, as well as for the Coordinating Centre to give a complete overview of the current status of the project.

We would like to thank all the investigators who attended the meeting and contributed to its success, for their involvement and participation, comments and discussions. We would also like to thank the EAS and all the organisers for their efforts in coordinating a group from all over the world and in delivering a successful meeting.



FHSC Booth

This year, our booth within the main EAS stand served as the FHSC base during the Congress. The booth was constantly attended by members of the Coordinating Team, and proved to be very useful for advertising the project, meeting new colleagues interested in the initiative and giving practical demonstrations on the use of the FHSC Website. Many NLI's stopped by throughout the congress to simply say "hi" or for general queries related to FHSC. The booth hosted also flyers brought by NLI's related to FH initiatives in their own countries.



FHSC Meeting Program

The meeting program was divided in three main sections, in order to give adequate relevance to the several aspects of the collaboration. The first session from the Coordinating Centre (CC) was devised to give the attendees a complete overview on the status of the project. In addition to the general topics presented in Prague in 2017, this year the presentation from the CC was split in three parts, in order to cover in more details the fundamental aspects of all the work behind the FHSC machine: management, IT and scientific aspects. A summary of the slides presented is available for download to registered NLI's on the FHSC Website. The second part of the meeting was dedicated to updates and initiatives from some of the National Lead Investigators, this year Prof T. Freiburger (Czech Republic), Prof R. Santos (Brasil), Dr I. Ruelle (Canada, on behalf of Prof J. Genest), Dr M. Bourbon (Portugal), Prof M. Ezhov (Russia) and Ms A. Le (Vietnam, on behalf of prof Huong). All the presentations have been extremely interesting and valuable, and we would like to thank the speakers for contributing with their experience to the meeting. The third and last part of the meeting was covered by Ms Jules Payne from FH Europe, who highlighted the important role of patients organizations in raising awareness on FH, and by prof A. Catapano, with updates from the EAS.

Overall, all of the attendees have provided positive feedback on the meeting, and the comments and suggestions will be useful to organize and improve the next FHSC Meeting, in conjunction with the EAS 2019 Congress in Maastricht (Netherlands). The afternoon ended with closing remarks from prof Ray, who once again stressed how this unique collaboration is important and effective to ultimately fulfill the main FHSC aim, to raise awareness of FH in the world and improve the care and management of patients affected by this disease. The status and reach of FHSC at the moment allow us to say quite confidently that FHSC is ready to "...make the impossible, possible!".



Networking dinner

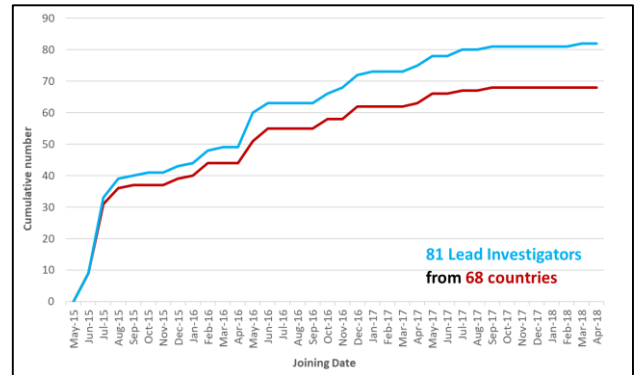


The networking dinner was a further and fun opportunity to network and to strengthen professional and friendship bonds amongst us. The dinner was held at the Sana Lisboa Hotel with an attendance of 60 delegates, based on a typical Portuguese and, of course low cholesterol, cuisine!

From the inclusion of the first countries in 2015, FHSC has consistently grown in reach and popularity globally. As per the end of May 2018, FHSC counted **68 countries** and **81 National Lead Investigators (NLI)** involved, making the project the global leading initiative in the field of FH.

One of the main objectives of FHSC is to raise awareness of the disease and to empower the medical and the global community to achieve a global policy change. Hence, FHSC can offer:

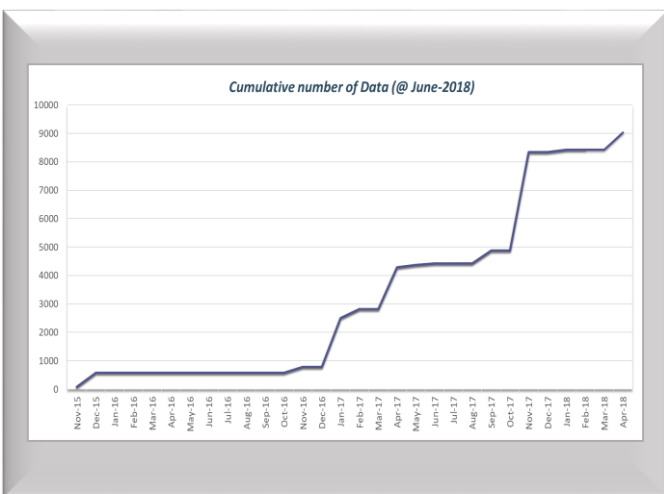
- support to collaborators to establish or develop an FH registry in their country;
- inclusion in a global network of FH experts who share experience and information;
- participation in the EAS annual congress;
- distribution of informative material.



Inclusion in FHSC is a binding agreement made official by a **Data Sharing Agreement**, document that has to be signed by the parties, and complies with the new EU GDPR directive. The agreement lays the basis of the collaboration covering legal issues, data and results ownership, obligations and publication rights. In particular, it makes compulsory the sharing of only de-identified FH data, whose ownership is retained by the sending NLI. To date, 80% of the NLIs has signed the agreement, where the remaining 20% has the document under review by their respective ethical committees.

Active involvement in FHSC, allows NLIs to participate in **high impact publications** that may derive from the activities of the project. Since 2015, FHSC has produced two articles in *Atherosclerosis* and *Atherosclerosis Supplements* where the NLIs are listed as authors (FHSC Investigators, *Atherosclerosis*, 2015. 243(1): p. 257-259, and FHSC Investigators, *Atherosclerosis Supplements*, 2016. 22: p. 1-3). Currently, a third paper is in preparation to submission to *Atherosclerosis*, consisting of a collation of short reports on FH management and activities in each participating country. This manuscript will be the first available complete overview of the current FH situation in all the FHSC countries.

FHSC relies on a **centralized data management** system that has been developed and tested throughout the years 2016 and 2017, eventually launched and made available to all collaborators in January 2018. The past two years have been crucial in the design and customization of an IT platform that would match the requirements of security and facility in data handling.



As per May 2018, the FH Registry includes ca. **9000 cases** from **21 countries**, with currently ca 8,000 cases already processed. The **FHSC Data Dictionary** is being produced by the FHSC Coordinating Team, consisting of a large compendium of FH data variables to serve as a guideline to the NLIs for their data collection. The aim of the document is to provide collaborators with a complete list of variables of interest for the project, to support the creation or the development of FH Registries. The resource will be available for free for all the FHSC investigators through the FHSC website.

The FHSC IT Team is designing a **data collection app** to be integrated in the FHSC Website, where NLIs will be able to enter individual data in the absence of a pre-existing Registry, to produce their customized FH Registry online within the secure FHSC Servers.



Thank you and see you next year in Maastricht, 2019!

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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