

EAS
FHSC



NEWSLETTER

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Issue 19

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FH Studies Collaboration

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Follow us:

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

FHSC Prepare for their Closed Annual Meeting

EAS Familial Hypercholesterolaemia Studies
Collaboration (FHSC)

**Steering Committee Closed (exclusive to invitations
only) Annual Meeting**

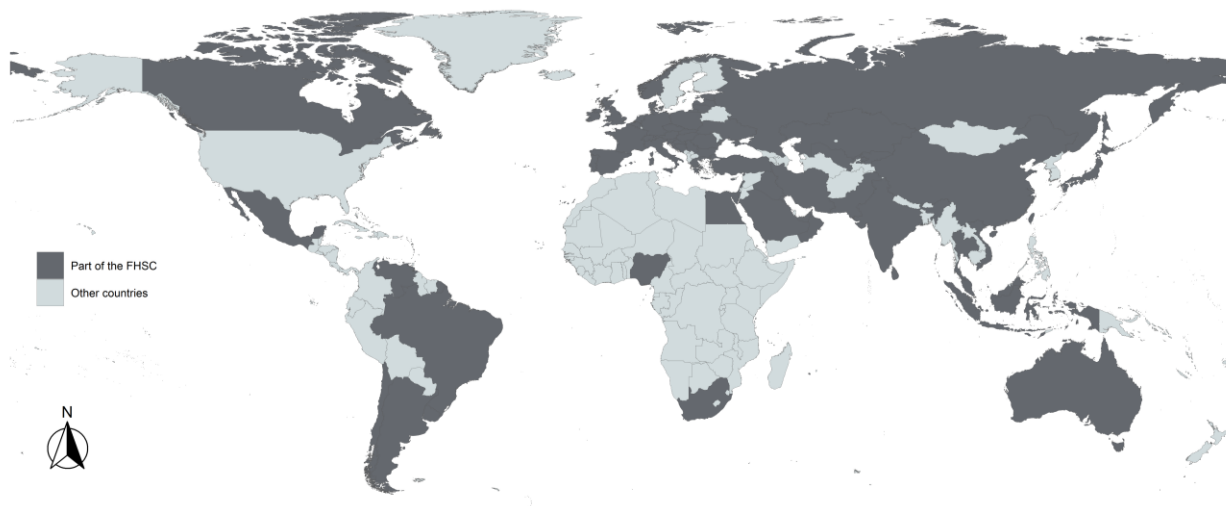
of approximately 100 invitees will be held on the
morning of

Sunday 22nd May 2022



In association with the
90th EAS Congress 22nd – 25th May 2022, Milan, Italy

The EAS FHSC now spans 67 countries (see shaded map below) and includes 80 Lead Investigators; specifically the National Lead Investigators are listed [here](#). EAS FHSC Registry includes 68,413 cases across 66 countries.



Become part of the expanding 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, we would like to hear from you!

For enquires contact info@eas-fhsc.org

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 'A global perspective on FH: Cross-sectional study from the EAS FHSC'](#)

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. Ask the Coordinating Centre for more details.

Interested to contribute an article (FH news, publications, events, etc) to the next EAS FHSC Newsletter?
Please contact: info@eas-fhsc.org

Worldwide Directory of Lipid Clinics and Patient Support Groups


This article presents latest statistics on:


- listed clinics & patient groups
- search activity by country

Locations:

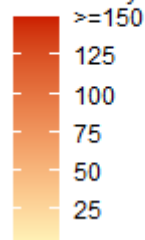
 Clinics

Listing of patient organisation(s) by country:

 No organisation(s) listed

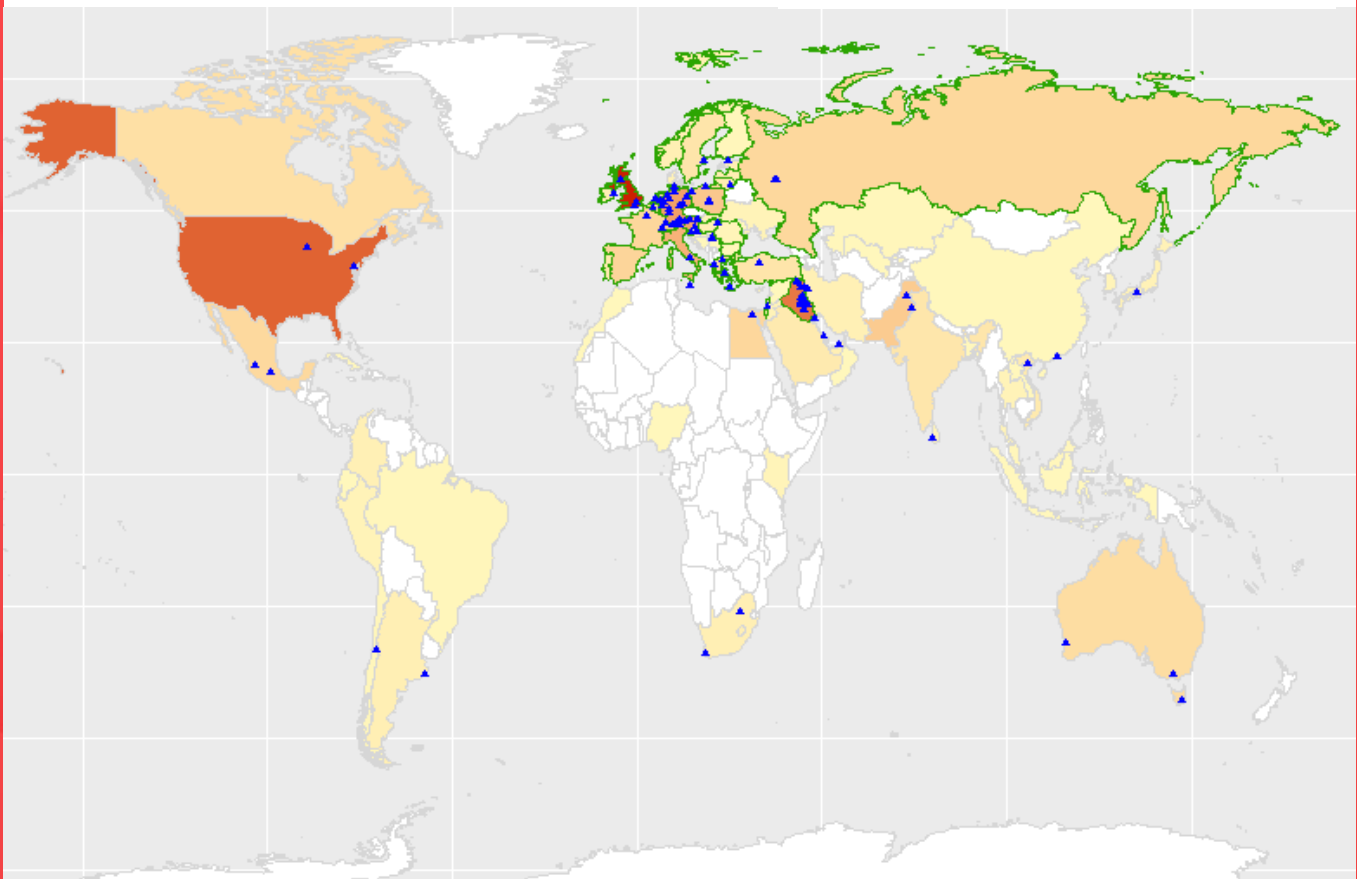
 Organisation listed

Number of unique users who searched in country:



Key Points:

- This Directory is in continuous development; more clinics & patient support groups need to be registered, particularly in south/south-west Europe and beyond.
- There has been a huge demand for this tool in US, Canada, India, Mexico, Saudi Arabia & Australia, but currently there are few/no clinics nor patient support groups listed in those regions.
- Although there are also searches made in some African, Asian and South American countries, very few clinics are listed there.



Follow this link to register your lipid clinic and/or patient support group
<https://findmylipidclinic.com/#/clinician-interface/listmyclinic>

MENA and AFRICA FH awareness campaign

Huge achievement in our international initiative to increase FH awareness in MENA and AFRICA since we established collaboration with colleagues and first lipid clinics in both Yemen (Sana'a Lipid clinic, est. Jan-2022) and Afghanistan (Herat lipid clinic, est. Feb-2022), with the patients' interest as priority.

We continue guiding these colleagues on how to develop their clinics into a unique healthcare service for FH patients and to educate other colleagues as well as the public about this genetic disorder.

Recently we also established Islamabad paediatric lipid clinic in Pakistan in collaboration with our colleagues in Pakistan (see article below for more information).

Dr. Mutaz Alkhnifawi, FHSC National Lead Investigator of Iraq



Launch of Pakistan's First Paediatrics Lipid Clinic

First Paediatrics Lipid Clinic launched Jan-2022 in Shifa International Hospital (SIH), Islamabad, Pakistan.

At the launch, Director of Research at Shifa Tameer-e-Millat University Prof. Sadiq provided an introduction on FH and the registry. Also, the President of Iraqi Lipid Clinics network Dr. Al-Khnifawi explained the significance of Paediatrics Lipid Clinics and why diagnosis at an early age is key to the management of FH. Head of the SIH Paediatrics department Prof. Malik officially launched this lipid clinic and acknowledged the efforts of Dr. Al-Khnifawi and Prof. Sadiq for establishing this first paediatrics clinic in Pakistan. "The collaboration with International Atherosclerotic society (IAS) will help to improve patient management", Prof. Malik added. Dean of the Faculty of Health Sciences Prof. Amir also welcomed the initiative of this first Paediatric Lipid clinic and agreed that we are now moving towards "prevention" and that this paediatrics lipid clinic will help in early diagnosis of dyslipidaemia and create awareness among general public. Finally, Prof. Aslam concluded with expression of appreciation and emphasised that all healthcare staff from the departments of paediatric, cardiology and clinical nutrition etc should work in unison to manage FH.

Prof. Fouzia Sadiq, FHSC National Lead Investigator of Pakistan



Homozygous Familial Hypercholesterolaemia Clinical Collaboration (HICC)

Several years after the Homozygous Familial Hypercholesterolaemia Clinical Collaboration (HICC) consortium was initiated, we recently celebrated our publication in [The Lancet](#) entitled 'Worldwide experience of homozygous familial hypercholesterolaemia: retrospective cohort study', describing the largest global dataset on homozygous (Ho) FH to date. This milestone achievement, which would not have been possible without the commitment of the many clinicians involved, hopefully marks the first of many research outputs to come from the consortium.

On 1st February we organised a virtual meeting attended by over 70 members from all over the globe during which we celebrated our collaboration and planned and discussed next ideas. The lively discussion yielded a long list of project ideas which are currently being tackled in smaller subgroups of collaborators.

The community, and the rich dataset it has compiled, offers unique opportunities to study issues related to HoFH that we are simply unable to answer through studies performed in single-centers. To name a few topics, the complication of aortic stenosis, the effects of lipoprotein apheresis and differences in cardiovascular disease between both sexes in patients with HoFH are now being studied in greater detail.

We hope that the results of these projects will increase our knowledge on this rare lipid disorder and, ultimately, improve care for the patients living with it.

If you have questions or would like to become involved in HICC, please send a message to:

coordinator@eas-hicc.org or t.r.tromp@amsterdamumc.nl

By Dr. Tycho Tromp

Leaving no one behind – a webinar on Homozygous (Ho) FH

On the occasion of Rare Disease Day 2022, FH Europe hosted [a special webinar](#) on Monday, 28th Feb in collaboration with the EAS. The topic of the event, titled Leaving no-one behind: creating a better future together for all people living with rare and severe FH, was inspired by the latest events in the international FH advocacy space. That includes the [High-level Technical Meeting on FH child screening](#), the recent findings published [in the Lancet](#), and the results from the metanalysis shared in the [European Journal of Preventive Cardiology](#).

The event brought together a multi-perspective panel representing the voice of scientists and clinicians, people living with HoFH as well as caregivers, international advocates and policy influencers. The focus of the discussion was the need to build on the recent scientific learnings to positively influence the national and the European health policies, the role of patients' organisations, scientists and clinicians in order to improve lives of HoFH patients. On the panel, moderated by Magdalena Daccord, FH Europe, we heard from Thanos Pallidis from LDL Greece, Michelle Watts, USA, Prof. Kausik Ray, UK, Nicola Bedlington, Austria, and Dr Marius Geanta from Romania, to provide an additional perspective in the context of the humanitarian crisis we are experiencing as a consequence of the events in Ukraine.

The event attracted 250 registrants, with 120 live participants. It was live streamed on Facebook, Zoom with simultaneous translation (German, Italian, French). It can be rewatched [here](#).

Magda Daccord, FH Europe Chief Executive

FREE WEBINAR

**Leaving no-one behind:
Creating a better future together for
all people living with rare and severe FH**



Speakers:



Magdalena Daccord
CEO, FH Europe
Switzerland



Thanos Pallidis
Patient Perspective
LDL Greece, Greece



Michelle Watts
Caregiver Perspective
Avery's Fight, USA



Prof. Kausik Ray
President, EAS
UK



Nicola Bedlington
Sr Policy Advisor, FH Europe
Austria



**Monday, 28 Feb 2022
6 PM to 7 PM CET**

**Register at
bit.ly/FHRareDisease22**