

Spring 2024 Issue 27

NEWSLETTER

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HEADLINES: New FHSC publication

The Lancet

Volume 403, Issue 10421, 6-12 January 2024, Pages 55-66

Familial hypercholesterolaemia in children and adolescents from 48 countries: a cross-sectional study

The Lancet recently published the FHSC findings on the children/adolescent dataset within the FHSC registry. The main findings were that children/adolescents are currently not the primary focus of detection strategies as they are found after their parents are diagnosed first. We need to move towards identification of FH in children/adolescents through LDL-C measurements and/or genetic confirmation as classical FH-related physical signs were uncommon. In fact, we can distinguish children/adolescents with FH from those without FH using LDL-C measurements from as early as the first year of life.

Children/adolescents with FH will be missed if existing clinical diagnostic criteria are used on, even when they are adapted to this population group. The children/adolescents are largely on monotherapy but still had very high levels of LDL-C. Boys were more likely to reach guideline-recommended LDL-C goals than girls. The guideline-recommended LDL-C goals were reached on using combination therapy.



GLOBAL NETWORK & REGISTRY



FHSC spans 75 countries and includes 91 <u>National Lead Investigators</u>. The FHSC Registry includes approx. Approx. 75K cases across 67 countries.

GET INVOLVED

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 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 Results: 'A global perspective on FH: Cross-sectional study from the EAS FHSC'
- Overview of a collaborative global effort to address the burden of FH
- <u>Familial hypercholesterolaemia in children and adolescents from 48 countries: a cross-sectional study ScienceDirect</u>

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.

Worldwide Directory of Lipid Clinics & Patient Support Groups: findmylipidclinic.com

For more information: Stevens et al. EAJ 2022;2:37-40

FHSC EAS Familial Hypercholesterolaemia Studies Collaboration

GLOBAL NETWORK & REGISTRY

Call to National Leads to share follow-up data with the Global Registry – EXTENDED DEADLINE APPROACHING



In July 2023 a call was made by email to National Leads to share FH follow-up data with the global registry. This graph shows the participating countries that had already shared follow-up data before that call. As follow-up data continues to be shared, the Coordinating Centre expresses gratitude to the National Leads for their contributions thus far.

The deadline for the call for National Leads to share follow-up data with the global registry has now been extended to <u>10th April 2024</u> for their country to be included in the next upcoming studies, which are reliant on follow-up data to pursue research beyond cross-sectional designs.

National Leads are welcome to contact the Coordinating Centre for more information regarding sharing their follow-up data by replying to the emails they received related to the call for data.



NATIONAL LEAD INVESTIGATORS' REPORTS

Fighting Fake Medical News Symposium (Role of Media)

collaboration with In the Journalists Syndicate in Diwaniya City (180Km to the South of the Capital Baghdad) and College of Pharmacy, Al-Qadissiyah University, the Iraqi Lipid Clinics Network arranged a symposium specially dedicated for Journalists about their role in fighting 'Fake' medical news in social media related to atherosclerosis and cardiovascular health to undermining the role of healthcare providers.

The symposium, hosted by the College of Pharmacy, was covered by the official Iraqi TV channel.



The attendees agreed to participate in this fight and to expand our team to include a representative from the City Council and the Supreme Police Authority in the City to yield the best results.

National Lead of Iraq Dr. Mutaz Al-Khnifsawi



Interested to contribute an article (FH news, publications, events, etc)?

Please contact: info@eas-fhsc.org