

# EAS FHSC NEWSLETTER

Issue 15, February 2021

## Issue 15

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## The Latest

### EAS FHSC Steering Committee Annual Meeting 2021

The FHSC Steering Committee Annual Closed Meeting 2021

will take place virtually on

Sunday 30<sup>th</sup> May 2021 at 9:00 am CET

in conjunction with the 89<sup>th</sup> EAS Congress 30<sup>th</sup> May – 2<sup>nd</sup> June 2021.



Invitations will be sent by the EAS to the FHSC Network in due course.

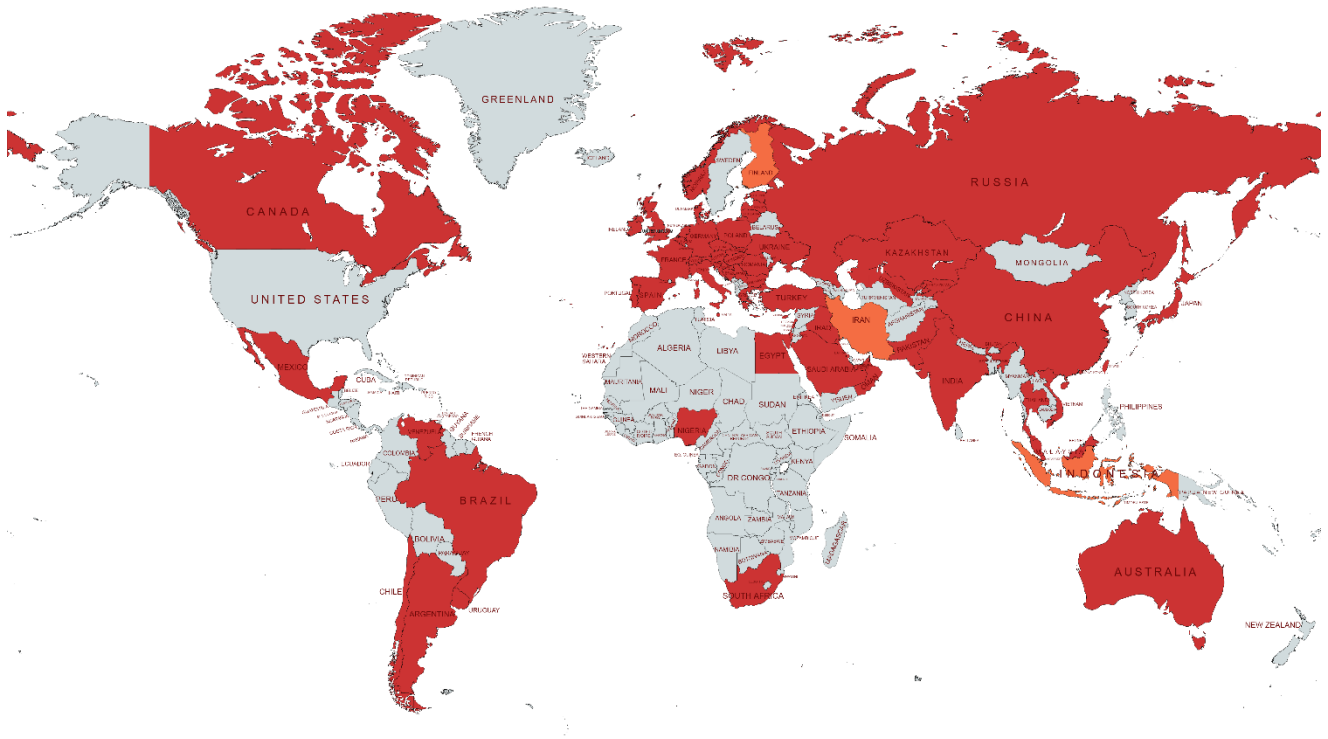
## FH Data on Children

The Coordinating Centre sincerely thanks all EAS FHSC National Lead Investigators (NLIs) and Collaborators that have contributed data on children to the Global Registry, which has now been locked for further submission of data on children. We are now preparing this large dataset for comprehensive analysis and interpretation regarding, but not limited to, the identification and management of FH in children worldwide.

The Registry currently includes >11,300 children from 48 countries on all continents. The results will be presented at the Closed Steering Committee Meeting and will be submitted for publication in peer-reviewed journals and congresses. NLIs are however invited to continue sharing data with the EAS FHSC for future analyses.

## EAS FHSC Global Network and Registry

**Eighty-two FHSC Lead Investigators**, with the National Lead Investigators listed [here](#), span **67 countries** of which 64 have contributed (**red**) to the FHSC Global Registry thus far and contributions are expected from others (**orange**) in the network as shown in the shaded map.



**Approximately 64.6K Cases Registered Across 64 Countries (Shaded Red)**

## 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** ([CT.gov Identifier: NCT04272697](https://www.ct.gov/Identifier/NCT04272697))?

If so, we would like to hear from you!

For enquires contact [info@eas-fhsc.org](mailto: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 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.

## Mexican FH Registry



The Mexican FH Registry recently published the article 'FH in Mexico: Initial insights from the national registry'. This is the first analysis of captured data since the registry was established in 2017. This article represents the efforts of more than 30 physicians, who form part of the Mexican FH Group, under the leadership of Dr. Carlos A. Aguilar-Salinas. This article provides an insight into the characteristics of patients with FH in Mexico, and highlights areas of opportunity where the current approach to this disease can be improved.

Over the past three years, FH Awareness Day has been commemorated in Mexico. We have held conferences with collaborators of the registry and educational events for patients. This has expanded the registry's impact among healthcare professionals and patients. Sessions for patients have not only been educational but have also provided a supportive environment for sharing personal experiences. In 2020, our virtual sessions with collaborators permitted active discussion, and enhanced enthusiasm and motivated participation in the registry.

Currently 60 physicians and researchers in Mexico are actively involved in contributing to this project and more than 750 patients have been registered to date. This year we hope that the Mexican FH Registry will continue to grow and with greater use of social media, outreach and involvement of more people. The ultimate aim is to positively impact the lives of FH patients in Mexico.

We are proud to form part of the EAS FHSC.

**Dr. Carlos A. Aguilar-Salinas,**  
**FHSC Co-NLI of Mexico**



### Grupo Mexicano de hipercolesterolemia familiar



<https://www.fhmexico.org.mx/>



## The VRONI and CoVAK-Studies



Bavaria successfully launched a programme for the detection of heterozygous FH. The VRONI study invites children aged 5 to 14 years to participate in screening during their routine paediatric visits. The screening is based on capillary blood LDL cholesterol measurements. Molecular genetic analysis for FH is performed on individuals exceeding LDL cholesterol values of 130 mg/dL (3.42 mmol/L), i.e. the 95<sup>th</sup> percentile in this age group. FH-positive children are registered and treated by specialised paediatricians and cardiologists. Furthermore, qualified training centres offer affected families FH-focused training courses. For first degree relatives of FH-positive children reverse cascade screening is recommended to identify affected family members.

The VRONI study started in September 2020 with more than 250 participating paediatricians in Bavaria. Overall, 600 individuals were screened within the first three months. Approximately 60,000 children are expected to be enrolled in the

VRONI study until 2024. This population-based study will provide unique data on the epidemiology of FH in Southern Germany.

Given the current pandemic, a screening for SARS-CoV2 antibodies (the CoVAK-Study) will be incorporated under the umbrella of the VRONI study. The material not utilised for LDL-measurement and genetic testing will be submitted to an enzyme-linked immunosorbent assay (ELISA) and, if questionable, by a line immunoassay (LIA). Taken together, the VRONI and CoVAK studies will test the feasibility of a population-based FH screening and generate data on the SARS-CoV2 epidemiology in school children in Bavaria.

Funded by DigiMed Bayern and Deutsches Herzzentrum München.

**Prof. Heribert Schunkert,**  
**FHSC Co-NLI of Germany**

**Contributions by V. Sanin & W. Koenig**

## Launch of the Electronic FH Consultation Centre in Iraq



We officially launched the Electronic FH Consultation Centre in Iraq to provide knowledge and awareness of FH for both health care professionals and the general public/patients with FH, on 23rd December 2020 in collaboration with Jabir Bin Hayyan Medical University, Kufa, Iraq.

This Centre, run by two physicians, also provides patient follow ups and free consultations to support patients who were hesitant to meet their appointments during the pandemic.

The launch of this Centre was well received in the opening ceremony with the ILCN President addressing the audience about the network and distribution of lipid clinics in Iraq. Faculty staff and medical students attended.

See the Centre via this link  
[www.fhe-center.jmu.edu.iq](http://www.fhe-center.jmu.edu.iq)



**Dr. Mutaz Al-khnifsawi, FHSC NLI of Iraq.**

## HELLAS-FH Registry



HELLAS-FH Registry, established in 2016, now includes 21 recruitment sites and 2,059 enrolled patients. This past year HELLAS FH had abstracts presented in major international congresses, such as the 88th EAS Congress 2020 and the 56th EASD Annual Meeting 2020.

At the end of 2020 we received the 2nd Award for clinical research during the 9th National Congress of the Hellenic Atherosclerosis Society. The award-winning abstract evaluated the role of PCSK9i in patients with FH after a theoretical treatment up titration to maximum statin/ezetimibe combination. It was estimated that even after maximising conventional therapy, around half of FH patients would still be eligible for PCSK9i treatment based on the ESC/EAS 2019 Guidelines.

Moreover, a paper entitled 'Prevalence of non-coronary heart disease in patients with FH: An analysis from the HELLAS FH' has been provisionally accepted for publication in the Current Pharmaceutical Design, where we explored the prevalence of peripheral arterial disease, aortic stenosis, chronic kidney disease and non-alcoholic fatty liver disease in patients with FH.

The registry now shifts its key focus from identifying and recruiting FH patients to updating the database with follow-up information, since the need to monitor the progress of enrolled patients was emphasised at the End-of-Year Investigator Meeting.

### The Hellenic Familial Hypercholesterolemia Registry "Hellas-FH"



Dr. Evangelos Liberopoulos,  
FHSC Co-NLI of Greece

Contributions by C. Rizos

## OTHER NEWS

### LDL-cholesterol lowering and clinical outcomes in hypercholesterolemic subjects with and without a FH phenotype: Analysis from the secondary prevention 4S trial.

Vallejo-Vaz AJ, Packard CJ, Ference BA, Santos RD, Kastelein JJP, Stein EA, Catapano AL, Pedersen TR, Watts GF, Ray KK. *Atherosclerosis* 2021 Jan 12;320:1-9.

<https://doi.org/10.1016/j.atherosclerosis.2021.01.003>

Analysis from the 4S trial assessing the benefit of lipid-lowering with statins in secondary prevention (CAD) of individuals with LDL-C  $\geq 4.9$  mmol/L with or without an FH phenotype. The FH phenotype appeared to be associated with greater clinical benefit (including greater absolute risk reduction in all-cause mortality and major coronary events) with simvastatin versus placebo from a similar magnitude of LDL-C lowering as compared to individuals without FH phenotype.

## HoFH - Our rare opportunity to raise awareness internationally

**VOTE FOR  
THE YOUNG PATIENT ADVOCATE AWARD****ANTHANASIOS PALLIDIS**

“*Anthanasios's commitment to Familial Hypercholesterolemia patient advocacy at a local and European level has improved care for patients and the resources available to them.*”



EURORDIS  
Black Pearl  
AWARDS

LIVE ONLINE 17:00 CET  
24TH FEBRUARY, 2021



#EURORDISAWARDS2021

Thanos became a founding member and Vice-President of the Board of a Greek FH patient association in 2013, and progressed to become the President of the Board for a three-year term in 2015. He was also one of the early Trustees with FH Europe.

We are delighted that this year Athanasios “Thanos” Pallidis has been shortlisted from 1,720 nominees for the prestigious [Black Pearl Award](#) by EURORDIS in the Young Patient Advocate category in recognition of his work for the Greek, European and the international FH patient communities, and contribution to the global policy document – ‘Global Call to Action on FH’, national advocacy initiatives.

Every year [EURORDIS](#), a non-governmental patient-driven alliance of 949 rare disease patient organisations in 73 countries, hosts an international Rare Disease Day campaign with many ancillary events, including the Black Pearl Awards.

FH Europe wishes to expand on this incredible achievement and to raise awareness of HoFH. As part of specific efforts around inherited high cholesterol, we invite the wider FH community, including all the FHSC investigators, to actively help and to [cast a vote here](#). Ultimately, this is a rare opportunity to inform public of FH.

Officially the [Rare Disease Day](#) falls on February 29th, every 4 years. This year the actual awareness day will be celebrated on the last day of the month, with the awards event taking place on February 24th.

In parallel the FH Network is developing a campaign [Many Faces, One Heart](#), giving the condition a human face and highlighting some inspirational patients, who do not allow the disease to define them, as they continue in their pursuits of dreams and passions.



**FH Europe**  
The European FH Patient Network

**Magdalena Daccord,**  
**FH Europe Chief Executive**

Interested to contribute an article (FH news, publications, events, etc) to the next EAS FHSC Newsletter?

Please contact: [info@eas-fhsc.org](mailto:info@eas-fhsc.org) || [coordinator@eas-fhsc.org](mailto:coordinator@eas-fhsc.org)