

EFAPH: European umbrella for better care of haemochromatosis patients in the world

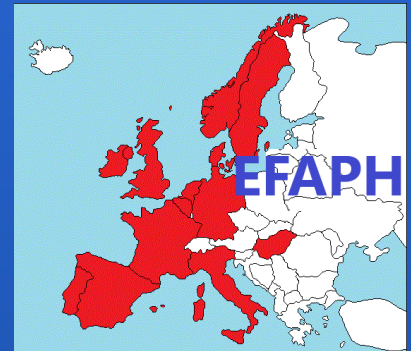
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INTRODUCTION

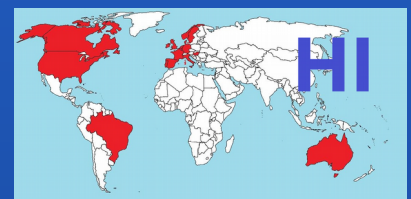
The European Federation of Associations of Patients with Haemochromatosis (EFAPH) has been working for hereditary haemochromatosis (HH) patients since 2004. HH is an iron overload disorder, mainly treated with regular phlebotomies. If not diagnosed and treated properly, this disease may cause severe tissue and organ damage. Among the EFAPH's initiatives, the improvement of the patients' life quality and research promotion are the priorities. Here we focus on the description of two main EFAPH's projects. Each one intends to help HH patients in understanding the treatment and symptoms and envisage helping the doctors in the search for appropriate treatment for their patients.

EFAPH joined efforts with Haemochromatosis International (HI) and together published therapeutic recommendations in HH

Not only existing guidelines are difficult for patients to understand, but also most of the recommendations are not shared among the different country health organizations. Based on the latest published evidence and the opinion of a large group of worldwide recognised experts, an objective set of recommendations was established in a comprehensible form for patients without medical training. Suggestions about the beginning and frequency of the treatment are indicated. These are also aligned with indications for the diet. Future therapies and the treatment with chelating agents in special cases are also part of the document. These recommendations help the medical staff to find the correct treatment, and patients to understand that they get the therapy they need. The recommendations have been translated to several languages and are available on the websites efaph.eu and haemochromatosis-international.org.



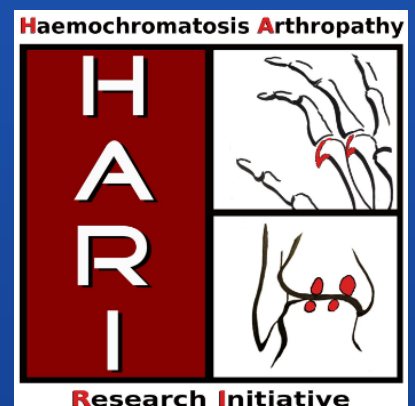
In red indicated EFAPH member countries



In red indicated members of HI

EFAPH established the Haemochromatosis Arthropathy Research Initiative (HARI) group

HARI was established in 2016 by an international group of rheumatologists and patients' representatives, and is committed to improve the care of HH patients with joint problems. HARI produced a collection of guidelines for treatment of HH patients with typical or special arthritis problems and made a list of recommendations for HH-related osteoporosis as well. The aim is to help patients to understand their treatment possibilities more easily. These instructions have been translated to several languages and published on efaph.eu and on national HH websites. More recently, the HARI group became head of an EULAR (European League Against Rheumatism) task force to define classification criteria for HH arthropathy. This project is the first step towards a larger goal to promote research for a better understanding of the disease and to develop novel therapeutics in HH arthropathy.



CONCLUSION: These projects are good examples of the essential role of EFAPH: supporting its member associations to help their patients - and every HH patient in the world - to get better care.

Reference: Adams, P et al. *Therapeutic recommendations in HFE hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype.* Hepatology International 2018 Mar;12(2):83-86.

Acknowledgements: Pierre Brissot, Paulo Santos, Pascal Guggenbuhl, Stephanie Finzel, Patrick Kiely
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