MEDIA RELEASE

IS THE WORLD PUMPING TOO MUCH IRON?

World Haemochromatosis Week 04 – 10 June 2018

New research and new guidelines recommend early diagnosis and treatment for one of the world's most common genetic conditions.

Iron overload or haemochromatosis, is a serious condition in which too much iron is absorbed and stored in the body. It can cause liver cirrhosis, liver cancer, arthritis, diabetes and general fatigue.

World Haemochromatosis Week, which kicks off today, aims to strengthen awareness of iron overload as early diagnosis will result in better health outcomes for individuals as well as huge savings for a country's health care system[1].

Haemochromatosis groups worldwide, including European Federation of Associations for Patients with Haemochromatosis EFAPH, have joined in a push to raise awareness and improve the rate of early diagnosis of this prevalent but all too often overlooked condition.

Through international collaboration, a task force of haemochromatosis experts has agreed upon an objective, simple and practical set of therapeutic recommendations for managing hereditary haemochromatosis, which are applicable around the globe[2].

President Dr. Barbara Butzeck of EFAPH welcomes this landmark guideline, noting that although haemochromatosis the most common genetic disorder in Europe it is still widely under-diagnosed. "*About one in 200 people of European origin have the genetic predisposition for haemochromatosis and additionally, one in 7 people are carriers of the gene that causes it*"

"*Haemochromatosis is under-diagnosed, partly because public awareness of the condition is low but also because its symptoms, including fatigue, depression and joint pain, are confused with a range of other illnesses. When undetected and untreated, iron overload can result in premature death*," said *Dr. Barbara Butzeck*.

Although haemochromatosis is detected by simple blood tests, support groups around the world continue to hear familiar stories from people with significant health problems caused by a late diagnosis. Recent research by the Murdoch Children's Research Institute (MCRI) has shown that haemochromatosis should be treated even when iron stores are only mildly elevated.' [3]

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[1] De Graff, B et al. (2016, November 16*). Population Screening for Hereditary Haemochromatosis in Australia: Construction and Validation of a State-Transition Cost-Effectiveness Model.* PharmacoEconomics.

[2] Adams, P. et al. (2018, March 27). *Therapeutic recommendations in HFE hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype.* Hepatology International.

[3] Ong, Sim Y et al. *Reduction of body iron in HFE-related haemochromatosis and moderate iron overload (Mi-Iron): a multicentre, participantblinded, randomised controlled trial* The Lancet Haematology, Volume 4 , Issue 12 , e607 - e614 https://goo.gl/6ijumL

The tragedy is that so many people suffer harm unnecessarily when timely management of their condition is simple, safe and effective. Haemochromatosis can easily be managed through blood donations which remove iron from the body and a diagnosis of haemochromatosis should be no barrier to a normal life. Joining together world-wide to raise awareness of the condition should help prevent harm from haemochromatosis.

For further information, or to organise an interview please contact:

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For further information about haemochromatosis, visit the EFAPH website ***www.efaph.eu.***

FAST FACTS

- Untreated haemochromatosis can cause liver cirrhosis, liver cancer, arthritis and diabetes.
- Most common genetic disorder in Europe.
- Initial tests for haemochromatosis are simple blood tests called “iron studies” that can be ordered by your doctor.
- Treatment is simple, safe and effective. This consists of regular removal of blood, known as a venesection. The procedure is the same as for blood donors.

ABOUT EFAPH

The European Federation of Associations for Patients with Haemochromatosis is a not-for-profit support and advocacy group for people affected by hereditary haemochromatosis.

Missions:

- To raise awareness Haemochromatosis amongst the Medical profession and the Public in general
- To assist in setting up national awareness associations in all countries, to promote best available treatment and quality of life and give an active participation to the patients in clinical research

We believe that people with haemochromatosis are entitled to get early diagnosis and free regular treatment to prevent severe organ damage and premature death.