

HEMO NEWS EU

Bulletin n°8, May 2021 | The newsletter of the European Federation of Associations of Patients with Haemochromatosis

THE NEW PRESIDENT'S MESSAGE



Ketil Toska

Despite the pandemic, I am still excited about the possibilities of my leadership role in EFAPH. My vision is to grow the EFAPH family and

build a greater understanding of the health implications of Hereditary Haemochromatosis (HH) not just in terms of organ damage but also in lessening the effects of HH on daily lives. Contributing to the spread of this knowledge amongst medical experts, GPs and political health workers is my heart-felt conviction.

I am 55 years old, a patient, married and live in Bergen, Norway working as a software company manager. As Chief Executive and later President, I have run the Norwegian Haemochromatosis Association since 2007 and am also a member of the EFAPH and HI Boards. I hope to serve you well as President, looking forward to the challenges ahead. ■

EFAPH HONOURS FRANÇOISE!



Dr Françoise Courtois

As a founder member and General Secretary of EFAPH for many years, Françoise Courtois was engaged in creating many patient associations, integrating EFAPH into important European institutions, and developing

documents promoting awareness of HH. The number of contacts she established, the fundraising events and travel she undertook, have been truly amazing; this tireless activity always accompanied by her natural kindness and French elegance. Besides all this, Françoise is also active in charity work recently receiving the highest French distinction: "La Légion d'Honneur". Merci beaucoup Françoise, we will miss you but are grateful that you continue as a Board member and office manager. ■



TWO AGMS

There was no Hemonews last year due to the pandemic. This year, therefore, we report on two AGMS: the Heidelberg 2019 AGM (9/5/2019, joint with HI) and the 2020 Zoom AGM (5/12/2020). The 2019 AGM was held in the amazing European Molecular Biology Institute Building following the International Biolron Meeting, allowing prominent scientists and clinicians in the iron field to participate. Dianne Prince (HI) and Françoise Courtois (EFAPH) gave an overview of the past years' activities including developments in EuroBloodNet, European Patients' Forum, Eurordis and the HH Arthropathy Research Initiative. Several Chinese scientists and clinicians attended giving accounts of the incidence of HH in China. The AGM concluded with a review of 2018 highlights

of EFAPH and HI member associations.

The 2020 AGM was held by Zoom with 31 attendees from 13 EU countries. After an overview of EFAPH, President Ketil Toska introduced a survey of patients' needs to focus the efforts of the scientific committee. Prof Graca Porto then reported the novel formation of a joint scientific committee (JSC) for EFAPH and HI. These and other initiatives are discussed further on page 3. A debate on the effects of the pandemic on HH patients followed, the results of this are reported on page 2. Hopefully, the next AGM will follow the European Iron Club Meeting in September, 2021 (Oxford, UK). Minutes and presentations for these AGMs are available on the EFAPH website. ■

Calendar 2021

February 28th: International Rare Diseases Day

May 12-14th: EURORDIS Membership Meeting (online)

May 20th: ERN-EuroBloodNet- Scientific and Strategic Board Meeting (online)

June 1-7th: World Haemochromatosis Week

June 2-5th: EULAR Congress, Paris, France

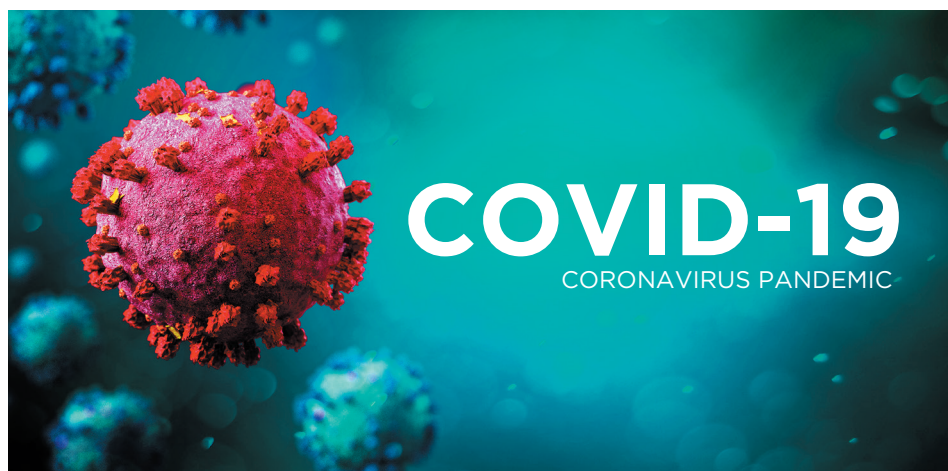
June 14th: World Blood Donor Day

June 17th: EURORDIS General Assembly (online)

September 5-8th: European Iron Club Meeting, Oxford, UK and joint EFAPH and HI AGM
September, 9th

October 26-29th: EPF Annual Congress

October-November: ERN-EuroBloodNet: Board of Network Meeting



COVID-19 and Iron Zoomposium

An international online symposium in September 2020, organized by the European Iron Club, was devoted to the topic "Iron and Covid-19". The main points emerging were that there is a marked drop in plasma iron reflecting the intense inflammation that develops in this infection. The lower the plasma iron, the more severe the Covid-19 infection, a severity reflected by the need for hospitalization and as-

sisted ventilation. One mechanism to explain this fall in plasma iron involves an increase in hepcidin production. This hormone regulates iron metabolism and increases in inflammation. No data are available as yet to indicate that HH patients are at increased risk from Covid-19. Further studies to elucidate the relationship between Covid infection and iron overload diseases are envisaged. ■

Impact of covid-19 on Member Organisations

Member organisations were surveyed about the impact of the pandemic presenting their replies at the 2020 EFAPH AGM. Some countries (Germany, Austria, Sweden, Denmark and Poland) reported virtually normal treatment whereas others (Spain, Portugal, Norway, France, Hungary, the Netherlands and Italy) saw disruption ranging from no/reduced phlebotomy to increased waiting times and telephone consultations. Generally patients were afraid to go for treatment. All countries rose to the challenge of lockdowns by using video-conferences, online-meetings and lectures.

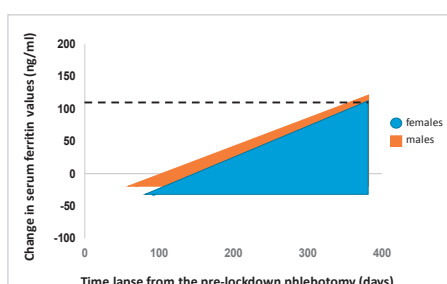
There were particular problems reaching members in Hungary. All countries saved money and there was better availability of meeting participants. A report by Alberto Piperno and colleagues described marked anxiety in 54 Italian HH patients due to fear of covid infection, unknown additional risk, decreased standard care and lack of support.

“ A significant increase in ferritin observed with time, predicting an increase of 100 ng/ml after one year without treatment. ”

In Portugal, the consequences of stopping maintenance treatment during lockdown have been followed as changes

in patients' serum ferritin values with time lapse between pre and post lockdown phlebotomies. The

figure (courtesy of Prof G.Porto) shows that a significant increase in ferritin was observed with time, predicting an increase of 100 ng/ml after one year without treatment which is unacceptable for the standards of maintenance treatment. ■



Maria de Sousa

EFAPH is saddened to hear of the COVID-19 related death of esteemed immunologist, Professor Maria de Sousa of the University of Porto, Portugal. From 1978 Prof de Sousa dedicated herself to investigating the



Pr Maria de Sousa

function of the immune system in protection against iron toxicity, extending this to study the immune system in HH patients. Her great contributions will be remembered and her inspirational presence greatly missed.



Welcome Miriam!

EFAPH welcomes Miriam Forde, the new Executive Director of the Irish Haemochromatosis Association (IHA). Miriam has an extensive commercial and non-profit management background and has held senior executive roles with national and international charities in the medical, health and international development sectors in Ireland and the UK. As Head of Cork University Hospital Charity, Miriam and her team delivered a wide range of life-changing equipment, facilities and services supporting the provision of world-class patient care at Cork University Hospital, through donations and private philanthropy. We are delighted to have Miriam on board with the Irish Association!



Miriam Forde with Irish Association President Margaret Mullett

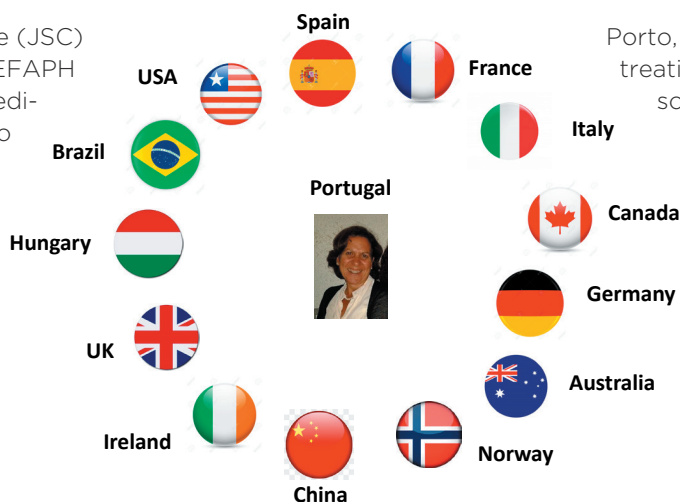
Thanks to EFS for their help!



STRONGER TOGETHER-EFAPH AND HI JOIN FORCES

A new joint scientific committee (JSC) has been formed serving both EFAPH and HI and including global medical and scientific experts. To test the coherence of the new JSC, members were asked to nominate the most relevant medical/scientific paper of 2019. The paper cited below* was regarded as most significant. Using the large UK Biobank community sample, the authors showed that HFE p.C282Y homozygotes experience substantial excess clinical illness, more common with age.

The head of our new JSC is Professor Graca Porto from the University of



Joint Scientific Committee
14 nations represented

Porto, Portugal who is both a clinician treating HH patients and a research scientist studying the role of iron in the immune response. Several exciting JSC projects are now underway including a survey to establish if and how a screening program for HH should be implemented. We welcome the new JSC and look forward to hearing further details of their enterprises.

*Pilling et al. Common conditions associated with hereditary haemochromatosis genetic variants: cohort study in UK Biobank. BMJ. 2019 Oct 23;367:l6157. doi: 10.1136/bmj.k5222 ■



HARI launches HA task force

Rigorous research into medical conditions such as haemochromatosis arthropathy (HA), and its application to patients, depends on the research findings being generated from people truly known to have the condition, thus accurate classification criteria are needed. HARI has successfully applied to EULAR (European League against Arthritis) to build a task force on HA classification criteria. A meeting was held in London in January 2020 to launch the task force involving rheumatologists, hepatologists, haematologists, GPs, nurses and patients from 11 countries, including Australia and USA. Classification criteria based on patients' symptoms, investigational signs, imaging and histological characteristics were listed and ranked into 15 candidate criteria after a lively discussion between experts and patients. The next step will be to test the 15 candidate criteria in a multinational, multicentre study, with the criteria finalized in late 2021.



EUROPEAN PATIENTS' FORUM CONGRESS



Howard Don - EFAPH EPF representative

In November 2019, Howard Don (UK) attended the EPF's first ever Congress on patient involvement in Brussels. The Congress hosted over 300 delegates, including patient advocates, healthcare professionals, health NGOs, academics and members from industry and national institutions. With a rich variety of speakers, the Congress considered opportunities and barriers for meaningful patient involvement in care, drawing on examples of effective practice. The patient voice was really highlighted as patients and advocates featured amongst keynote speakers and panellists. Perspectives from other

stakeholders such as regulators, academics, members of industry, national governments, health NGOs and EU institutions all contributed with tangible ideas to help integrate patient involvement into our health systems. Shared decision making between patients and clinicians optimizes care and better communication between disciplines could result in less appointments. So necessary for many HH patients!

In conclusion, this Congress contained much meaningful patient involvement and showed that now is the time to act and to build from our own evidence and stories. ■

Reports from our members

Nordic Perspectives



A surge in impetus to form new Nordic associations is underway. EFAPH president Ketil Toska is helping to set up an Icelandic group where there is strong interest in their FACEBOOK page. Recently Sweden has formed a society, now an EFAPH member, and most of Finland's HH patients live in the western part of Finland and tie in with a Swedish migration history. Many still speak Swedish as well as Finish: **A promising rapprochement!**

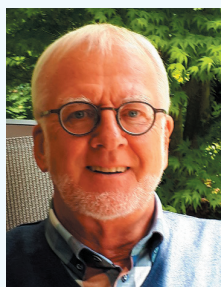
Kirsten Børgesen of the Danish Haemochromatosis Association (DHA) reports 3 principle recent actions:

- a new information brochure distributed to hospitals, clinics, GPs and physiotherapists
- proposed extension of the use of blood from HH patients in the induction phase from 3 to all 5 Danish regions
- DHA have joined the Danish Cancer Society (liver cancer being the most common complication in HH patients); this society provides valuable help to DHA in financial and logistical terms.

EFAPH salutes an interesting initiative in the Netherlands!

The Dutch blood bank organisation Sanquin accepts HH patients for phlebotomy and erythrocytapheresis, provided they are in the maintenance phase with ferritin levels of ≤ 100 ug/l. Interestingly Sanquin tests all "normal" donors for ferritin level, often discovering donors with raised values, possibly pointing to HH. These donors are then advised to approach their physicians for HH testing. This donor ferritin testing may provide insights into the incidence of HH in Dutch society, with the caveat that donors are not necessarily representative of the whole population.

A good example to follow!



Cees van Deursen:
HVN President

Making the best of a bad situation

The French EFS blood bank is abandoning phlebotomies to focus on their core activity: blood donation. Good news for HH patients meeting donation criteria but bad luck for the majority (70 %) who have no care! The French Federation of

haemochromatosis (FFAMH) is successfully initiating local HH care networks, encouraging EFS doctors to cooperate with hospital hepatologists to identify downstream care structures such as health centres and nurses either trai-

ned or in training to do phlebotomies. Patients can then be referred to trained nurses if necessary. FFAMH can provide nurses and hospital units with HH follow-up booklets, international guidelines and leaflets.

HI Photographic competition




2020 Winner:
Karine Coupal from Canada

HI invites all budding photographers to submit entries for their annual WHW photographic competition. Last year's theme was 'rust never sleeps' whereas this year the theme is inheritance or heritage. Closing date is 30th April, 2021 with a modest prize for the winner (see HI website for more details)!

<http://haemochromatosis-international.org>)

Don't forget:

**WORLD
HAEMOCHROMATOSIS
WEEK**
1-7 JUNE 2021

Too much iron? Time to screen!

Join us on
www.efaph.eu



Editorial Director: Ketil Toska Editorial Committee: France Briand, Françoise Courtois, Pat Evans
Other contributors: Kirsten Børgesen, Barbara Butzeck, Pierre Brisot, Cees Van Deursen, Howard Don, Miriam Forte, Margaret Mullett, Brigitte Pineau, Graça Porto
Conception: Infopro-Digital - impression: Duplitech St Malo



EFAPH: European Federation of Associations of Patients with Haemochromatosis
Federation Européenne des Associations de Malades de l'Hémochromatose
Ketil Toska (President) + 47 93 40 53 22 info@efaph.eu www.efaph.eu
Patricia Evans (Assistant) + 44 77 17 05 48 04 patriciajevans47@gmail.com