

# HEMO NEWS

Bulletin n°3 March 2015 | The newsletter of the European Federation of Associations of Patients with Haemochromatosis

## THE PRESIDENT'S MESSAGE



Dr Barbara BUTZECK  
(Germany)

**2014** saw new impulses in EFAPH actions: The question of blood donation was approached. The collaboration with the "Etablissement Français du Sang"

(EFS) was consolidated. A questionnaire regarding the acceptance of the blood of HH-patients in different EU countries was planned and presented at the AGM in Verona.

More and more rare forms of the diseases are coming into focus both on the patients' and researchers' side. The need for a network of Reference Centres or Centres of Expertise was confirmed.

I am looking forward to see you all at our next AGM on October 16<sup>th</sup>/17<sup>th</sup> 2015. The German HH-Association HVD as organizer will warmly welcome you in the City of Cologne, Germany. This meeting will be held together with the International Alliance of HH-Associations (IAHA). ■

## SCOOP ABOUT HAEMOCHROMATOSIS ON THE "ROUTE DU RHUM" TRANSATLANTIC SAILING CONTEST!



**T**hree days after Loïc Peyron (the winner of the race), on Thursday, 13<sup>th</sup> of November, Erwan Le Roux, won in the Multi 50 category on board FenêtréA-Cardinal. The standalone Breton crossed over the Atlantic in eleven days, five hours, thirteen minutes and fifty seconds. Note the new logo of the European Federation of Associations of Patients with Haemochromatosis (EFAPH).

The European and French Haemochromatosis Federations as well as

the associated regions/countries hail Erwan's victory and congratulate him wholeheartedly.

**Well done, Erwan!**

We are proud to count Erwan as one of our ambassadors. Thanks to him thousands of people have been made aware of haemochromatosis. The early diagnosis of the disease is necessary in order to avoid severe complications (joint pains, heart problems, diabetes, cirrhosis...). ■



**The New Logo where besides the abbreviation EFAPH, the full name of the association was added to bring a better visibility on Haemochromatosis.**

## Welcome to HVV, EFAPH's 13<sup>th</sup> association!



At the beginning of 2014 the Flemish Association for Haemochromatosis Patients in Belgium called HV Vlanderen (HVV), joined EFAPH. The association was represented at the AGM in Verona by the treasurer Mrs. Annick Vanclooster who gave an interesting talk on key-interventions for treatment and follow-up of patients with HFE-haemochromatosis. ■

## Calendar 2015

- June 2015:** European HH week  
A multiregional registry of HH rare forms
- September 2015:** phase 2 of GPs awareness campaign (France & Europe)
- October 2015:** Cologne AGM (EFAPH + IAHA)
- 25<sup>th</sup> November 2015:** Yves Henry piano concert, salle Cortot, Paris 17<sup>e</sup>
- December 2015 :** Blood donation and hereditary haemochromatosis survey.



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## The German Association

In 2014, the German Association HVD launched an approach to specialists in occupational medicine. This group of physicians often play the role of General Practitioners. During the German congress for specialists in industrial medicine in Dresden, April 2014, a poster about HH

early diagnosis was presented. This resulted in two studies starting at the end of 2014: 1. Immunological changes in the blood of HH-Patients. 2. Manganese and Iron in the brain of welders – in comparison to Parkinson and HH-Patients.

## The Hungarian Association



In Hungary, the public at large and General Practitioners are unaware of HH; during 2014, different actions were undertaken to improve their knowledge, in particular during the health-screening days (when people are sensitive to health problems). For these events, a special T-shirt with the logo of HBE was created.

## A new president for HBA (Haemochromatosis Belgian Association).



**Bernard Delwart,**  
HBA president

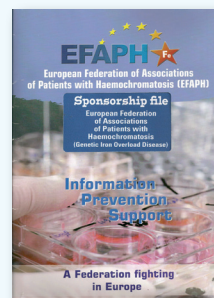
In 2014, Bernard Delwart replaced Anne Saille, as President of HBA. He will benefit from the dynamic contributions of Tanguy de Decker (Treasurer) and Anne-Sophie Snyers (General Secretary). A project to raise the awareness of General Practitioners of one of the regions of French-speaking Belgium is starting by the end of the year.

## The Swiss Association

The Swiss self-support group, active near St Gallen for years, has taken a big step forward by establishing a countrywide association, called Hämochromatose Schweiz, chaired by President Gerda Horn.



**A meeting important to note:**  
The next General Assembly of EFAPH  
in Cologne, Germany,  
October 16<sup>th</sup> and 17<sup>th</sup> 2015.



**New!**  
EFAPH  
sponsorship file  
2<sup>nd</sup> version

## A dynamic country: Portugal!



**Emerencia Teixeira (APH)** : EFAPH's webmaster

In addition to the above-mentioned survey on Blood Donation and to taking over the management of EFAPH's website, APH has organized for its 11th anniversary a symposium "Prevention of Risk or Risk Prevention?" targeted at GPs, sponsored by the Portuguese Association of General Practitioners. APH has issued a new booklet adapted from the original Australian document. A new slogan "1 in 500 Portuguese has a genetic risk for HH" is now widely used, amongst others on nice T-shirts. Worthwhile mentioning is also the contest by 100 students from 7 schools of V.N.Famalicao resulting in 27 videos/posters about HH.

## A successful campaign to make General Practitioners (GPS) HH sensitive: the Yvelines pilot project

Too often in Europe GPs are unaware of the diagnosis of Hereditary Haemochromatosis (HH). This was acknowledged by the European Commission in February 2012 and 5 recommendations were issued assigning a priority to the early diagnosis of this disease. France was the first country to take action. A pilot campaign aimed at the 920 GPS in the Yvelines district (78) was launched in September 2013. They were sent a simple, didactic document featuring "what should be done so as not to omit a HH case" as well

as a list of the specialized departments and phlebotomy centres in the 78 District. This action has had the following impact for the first 2014 half-year:

- 40% of the GPs have stated that they did receive the document, 95% of whom reported that they found it useful, among whom 50% stated having used it for a patient in the months that followed,
- 25% of the surveyed medical labs in the 78 District reported a + 5.7% increase in the number of ferritin tests and a +13.5 % in the

number of transferrin saturation tests.

- A 20% increase in genetic tests was reported by the 2 specialized labs (CERBA and BIOMNIS)\*.

The outcome is very significant and led to the launching of similar campaigns in Brittany (December 2014) and in the Paris/Ile-de-France Region (year 2015). Some of EFAPH member countries will follow suit, within the next few months, Belgium in particular.

\* 1<sup>st</sup> semester 2014 vs. 1<sup>st</sup> semester 2013, Dr F.Courtois

- Savoir-Fer, FFAMH news bulletin (France).

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