

TO ALL HAEMOCHROMATOSIS ASSOCIATIONS

Notice of Meeting World Iron Awareness Week Recommendations in haemochromatosis and General Update

Dear Haemochromatosis Colleagues

A year ago Haemochromatosis International (HI), previously known as the International Alliance of Haemochromatosis Associations, was formally established. Our objective is the advancement of the health of people with haemochromatosis. We seek to support the work done by the many patient-based groups around the world.

The purpose of this newsletter is to -

- invite your organisation to send a representative to our Annual General Meeting on 12th May 2017 in Los Angeles,
- let you know about our current activities,
- invite you to participate in World Iron Awareness Week, and
- invite your organisation to become a member, if you have not already joined.

Sixteen associations from fifteen countries have now become members of HI.

AGM with Biolron

The International Biolron Society have repeated their most generous offer of free registration for one representative of each member of HI to their 2017 meeting.

The meeting will be at the Luskin Conference Centre, UCLA, Los Angeles, from 7th to 11th May 2017.

In addition, they have most kindly enabled us to have a full day meeting at an adjacent site in UCLA on 12th May.

This will be our Annual General Meeting with all the usual reports and election of office bearers. The agenda will also include;

- A brief overview of recent scientific developments in haemochromatosis,
- An opportunity for all member organisations to share ideas and speak about their activities,
- A workshop on our development of a set of international recommendations for the treatment and management of haemochromatosis,
- An opportunity to contribute to HI's plans for the coming year.

The Recommendations Project

A survey of organisations that are members of HI and/or European Federation of Associations of Patients with Haemochromatosis (EFAPH) has demonstrated that many countries do not have standard guidelines for the management and treatment of haemochromatosis. Further, some guidelines are inconsistent.

There are several comprehensive practice guidelines such as those published by European Association for the Study of the Liver (EASL) and the American Association for the Study of Liver Diseases (AASLD). These are important, complex and thorough documents that are intended for clinicians. However, they are lengthy and not useful for the majority of patients.

We have established a **Therapeutic Recommendations in HFE Haemochromatosis Taskforce** with the following members -

<i>Paulo Santos Chair (Brazil)</i>	<i>Graça Porto (Portugal)</i>
<i>Brigitte Pineau (France)</i>	<i>Pierre Brissot (France)</i>
<i>Domenico Girelli (Italy)</i>	<i>Robert Evans (England)</i>
<i>Emerência Teixeira (Portugal)</i>	<i>Sonia Distant (Norway)</i>
<i>Ian Hiller (Canada)</i>	

The task force is preparing a draft set of recommendations and will be consulting with a range of eminent authorities with a view to finalising the document at our meeting in LA in May.

The aim is to have a set of recommendations which are brief, readily understood by patients and supported by a high degree of consensus.

World Iron Awareness Week

This week, which in 2017 will run from 1st to 7th May, was originally established by Beef and Lamb New Zealand to raise awareness of iron deficiency. However, the week having been established, we can also use it to also raise awareness of iron overload.

The week provides an opportunity for all haemochromatosis organisations to raise awareness by distributing a media release that draws attention to the incidence of iron overload, as well as iron deficiency, and the similarity of the symptoms for some people. We plan to prepare a draft release for members to consider and perhaps adapt to suit their local circumstances.

While this is a small beginning, with your support it has the potential to grow into a useful tool in raising awareness of haemochromatosis, as well as iron deficiency.

Information sharing

We have established our web site at <http://haemochromatosis-international.org> where you will find contacts and links for many haemochromatosis associations. Member organisations are encouraged to share some information about their services.

Our meetings at Cologne in 2015 and Innsbruck in April this year have also provided really useful opportunities for members to share and discuss activities, issues and resources.

Membership

Sixteen associations have now become members of HI.

I invite your organisation to become a member of HI, if you have not already joined. Working together can only assist in our common cause.

The membership fee is £20 sterling. Small organisations that have difficulty in such a payment may apply for it to be waived.

Payment by Paypal is available via the website

Payment can also be made by bank transfer to –

Metro Bank, 1 Southampton Row, London WC1B 5HA

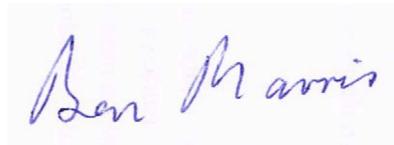
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In concluding our first newsletter I send best wishes in all your endeavours and I hope to see you in Los Angeles in May.



Ben Marris

President

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Haemochromatosis International Committee Members

President	Ben Marris	Australia
Vice President	Paulo Santos	Brazil
Past President	Robert Evans	UK
Secretary/Treasurer	Desley White	UK
Committee Member	Barbara Butzeck	Germany
	Howard Don	UK
	Emerencia Teixeira	Portugal

Honorary founding member

Prof. Pierre Brissot France