

Report of the fifth EFAPH Annual General Meeting

June 12th, 2009, Porto, Portugal



Welcome and introduction

Speaker: Jean Rialland, President

In attendance:

Representatives of Hemochromatosis Associations

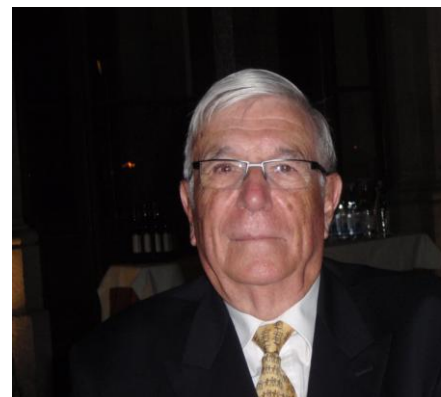
Rialland Jean	France
Brissot Pierre	France
Troadec MarieBérangère	France
Courtois Françoise	France
Lassale Jacqueline	France
BalagayrieJean Louis	France
Mullett Margaret	Ireland
Mullaney Francès	Ireland
Butzeck Barbara	Germany
Altes Albert	Spain
Stark Eddie	Spain
Porto Graça	Portugal
Melo Graça	Portugal
Cruz Eugenia	Portugal
Costa Manuel Joao	Portugal
Carvalho Joao	Portugal
Toska Ketil	Norway
Borch-Iohnsen Berit	Norway
Varkonyi Judith	Hungary

Apologies

de Decker Tanguy	Belgium
Gribaumont Anne	Belgium
Pietrangelo Antonello	Italy
Mac Donald Stuart	UK
Hulcrantz Rolf	Sweden
de Sterke Philip	Nederland
Morillon Philippe	France
Segaud Sophie Moisan Jean Paul	France
Moisan Jean Paul	France

Part Attendance (Guests)

St Pierre Tim	Australia (Perth)
Boillat Edgar	Switzerland
Koenig Gerry	USA (Iron Disorders Institute)
Vokurka Martin	Répubblica Tchèque
Mac Laren Gordon	USA (University of California)
Vujic Spasic, Maja	Serbie (Heidelberg Germany)
Fischer Roland	Germany (Hamburg)
Swinkels Dorine	Netherlands (Nymegen)
Fraga Jose	Portugal



Appendix 1 (email address of participants)

The President of EFAPH, Jean Rialland introduced the meeting by welcoming all present.

A good day to all of you

Before we open this general assembly, I want to say a great thank you to our friend Graça Porto and to her team for the way they have welcomed us in this beautiful city ...but it is true that our friends have already many connections with the French history.

It has been 5 years and half already, and in spite of a number of difficulties we have kept going forward, step by step, without haste, with those of our European fellow creatures who suffer from this same genetic ailment.

Unhappily some of our contacts have been impatient, and we are sorry the Dutch Association has resigned.

Today we welcome the representatives from other European countries, and from the world.

This is a very special day for me, for it will be the last one of my chairmanship.

The diploma I received yesterday testifies the work I did at EFAPH, it is also the result of what we all did together. Thank you to all of you.

All my wishes for the follow up of what you'll work at during the next years. You can be sure I will always stay attentive to what happens within EFAPH.

EFAPH members General presentations

On June 12th 2009 EFAPH held its 5th general assembly.

As noted in the order of the day (**appendix 2**), the different interventions and speeches were given in a clear and precise way. You'll find the different texts in appendix.

EFAPH History, Actions and Perspectives Speaker : Françoise Courtois



4 years of the European Federation's life, history, actions, projects were presented and detailed.

The work that was done during this period allowed us to build strong links and to position EFAPH in the area of Health and Prevention inside the European Community.

- It underlined the importance of this meeting, which was for the 1st time integrated to the IBIS (BIO-IRON) International Scientific Congress.
- Among the projects that were announced:
 - Keep opening up to new countries in the European Union
 - Organize an EU event day around the iron surcharge
 - Continue to support the establishment of a network of reference centres across Europe

(Appendix 3)

National Reference Center : The French Experience
Speaker: Pierre Brissot



Pierre Brissot presented data regarding the recent creation in France of a reference centre for rare iron overload diseases of genetic origin.

This creation is part of the national health plan for rare diseases. The iron centre, located in University Hospital Pontchaillou (Rennes) and coordinated by Pierre Brissot, works in close relationship with a series of “competence centers” scattered all over the territory as well as with the patient association FFAMH (french federation of associations of patients with hemochromatosis).

The roles of the reference centre, which benefits from financial support by the Ministry of Health, are to ensure the best care for the concerned patients and to guide specific clinical and basic research. It is hoped that a similar European network is created in the near future. EFAPH will be the natural partner at this at a European level.

(Appendix 4: selection)

EFAPH Strategic Plan Speaker: Barbara Butzeck, Frances Mullaney

Frances Mullaney and Barbara Butzeck gave a presentation outlining the overarching strategic plan of EFAPH. They explained how this is in keeping with the original goals and mission of EFAPH and detailed what the next steps are in terms of achieving these. They described the strengths and weaknesses of the previous work.

Frances with her knowledge of the political scene in Brussels presented the main EU health actors and explained how contact with such actors needs to be replicated at each national level to ensure consistent messaging. The established contacts to important umbrella organizations like EPF (European Patient Forum) and EURODIS should be consolidated.

Frances and Barbara pointed out that moving forward, EFAPH intends to have much greater communication with its members to ensure that their needs are being met and considered. Issues to be considered include: cost of treatment per country, sharing best practice in raising awareness, support for patient groups, capacity building, fund raising, medical education of health professionals, developing treatment guidelines, insurance levies, innovative treatments, and research.

It was also agreed that communication not only between members but also from EFAPH to an external audience would be improved. The EFAPH secretariat will undertake a review of the website.



European Guidelines Speaker: Barbara Butzeck – Graça Porto

Heinz Zoller, Innsbruck Austria, working on Clinical practical guidelines for Hemochromatosis on behalf of EASL discussed during the BIOIRON congress the implementation of a chapter on patient organizations with Barbara Butzeck, Margaret Mullet and Graça Graca Porto.

The audience was pleased to hear that a chapter on Patient organizations shall be implemented in the CPG. It was suggested trying to involve other specialist than hepatologist such as rheumatologists and others.

(Appendix 5)



International experiences and presentations

Our general assembly was able to profit by the presence at IBIS of international personalities who represented, on one hand Scientific and Medical Research, on the other patients' associations; they came to share with us what they had experienced in their different countries.

The Haemochromatosis Society of South Africa (HSSA – Kirsten Alberts and Roger Keyte) send greetings, apologize not being present and agree upon a future participation and also Sandra Thomas (President/Founder of **the American Hemochromatosis Society**) cannot participate but she assure a support for an International collaboration.

During the Biolron meeting (IBIS) EFAPH board members had the opportunity to have fructuous exchanges with Margaret Rankin (President of **The Haemochromatosis Society Australia**) but unfortunately she could not stay for EFAPH meeting.

The Canadian Hemochromatosis Society showed an interest to EFAPH and transmitted some informations upon the Society.

Speaker: Gerry Koenig (Iron Disorders Institute, USA)

Gerry Koenig from the Iron Disorder Institute USA explained that in their organization they have listed 10.000 names not only with hemochromatosis but also with anaemia. There is no reimbursement of the ferritin or genetic tests, and while the actual costs of the tests are low (10-20 US\$), the patients are charged \$ 200!. There is a high rate of under-diagnosis. He reported that there is a month of awareness already established which is June in USA and July in Canada.



Screening for Hemochromatosis and Iron Overload in multiple ethnicities
Speaker: Mc Laren Gordon (USA- University of California)

Screening for Hemochromatosis and Iron Overload in multiple Ethnicities. Lessons from the HEIRS Study

The **HE**mochromatosis and **IR**on Overload **S**creening (HEIRS) study (published Am J. Med. Science 2003) provided data on a racially, ethnically and geographically diverse cohort of participants in North America screened from primary care populations. There were 101,168 participants screening by testing for HFE C282Y and H63D mutations and measuring serum ferritin and transferrin saturation. In this overview, lessons from the HEIRS study are highlighted in the context of the principles of screening for a medical disease as outlined previously by the WHO.

1. Generalized population screening in a primary care population as performed in the HEIRS study is not recommended.
2. Genetic testing for hemochromatosis is well accepted with minimal risk of discrimination.
3. An elevated serum ferritin is very common, particularly in Asians, Pacific Islanders and African Americans and may not be an indication for phlebotomy. In the absence of HFE C282Y homozygosity, this finding usually does not represent an increase of iron stores > 4 g.
4. Transferrin saturation has high biological variability and relatively low sensitivity to detect HFE C282Y homozygotes which limits its role as a screening test.
5. Symptoms attributable to HFE C282Y homozygosity are no more common in individuals identified by population screening than in control subjects.
6. Mild increases in body iron stores in the range of 2-3 g were common in non-HFE C282Y homozygotes, but iron overload defined as iron stores > 4g was most common in Caucasian men who were C282Y homozygotes.
7. There may be a role for focused screening in Caucasian men with some debate about genotyping followed by phenotyping or phenotyping followed by genotyping.



Moral Report Ongoing Actions

President : Jean Rialland, Speaker: Françoise Courtois

See Powerpoint presentation below (Annexe 6)

This report concerns only half a year (7 months) since the St Gallen General Assembly was held in September 2008. Among the important achievements of EFAPH was the organization of a workshop held in Bucharest (Romania) in November 2008, which was summed up in a report sent to every members of EFAPH. This action can be used as a model for the same kind of actions in the other countries with which we have started relationships.

EFAPH was also represented at several other fora i.e. EU symposiums and forums, and we have participated in a number of general assemblies of EU associations and organizations of which EFAPH is a member (EPF, Eurordis ...).



Financial Report

In the absence of the treasurer Sophie Segaud, a summary of the financial report was presented and approved.

(Appendix 7)

Activity Report and project by national association

Country: Ireland

Speaker: Margaret Mullet



The IHA was started in 1995. At least **four board meetings are held every year**. The Directors are Margaret Mullett (Chairperson), Ann Campbell (Secretary), Brendan Gallagher (Treasurer), Rosaleen Mc Court, Fran Mullaney, Brendan Keenan, Denise Mc Auliffe, Ann Mc Grath and Kate Geoghegan.

The AGM takes place in Dublin on the last Saturday in May.

All work is done on a voluntary basis. The members pay an annual subscription of €20 or €10 if retired or unemployed.

The launch of the Impact Document on Haemochromatosis at the AGM of the Irish College of General Practitioners (ICGP) in Galway on May 9th was a great step forward in raising awareness of Haemochromatosis (HH). The document is a collaborative effort between the ICGP and the Irish Haemochromatosis Association (IHA). Clear guidelines for diagnosis and management are given and this publication should be welcomed and read by every GP in the country. This was one of the recommendations in the report which was presented to Minister Mary Harney in June 2006.

Ploughing Championship in Kilkenny

A stand was manned by members of the IHA for three days at the Ploughing Championship last September. The show which was attended by 150,000 people was a great way of raising awareness of HH. Many of those interviewed had never heard of Haemochromatosis. A recent survey showed that only 30% of people who were interviewed had heard of haemochromatosis

Regional Meetings in 2008 and 2009

A series of very successful information meetings were held in Castlebar, Clonmel, Tralee, Dublin, and Nenagh. These meetings were attended by 80-100 people. The added bonus was that if a meeting was held in a particular area, the local radio and newspaper were happy to feature an article on HH

Fund-raising

Mini Marathon. Board members and IHA members participated in the marathon and in 2008 over €8,000 was raised. Thanks to all those who participated and supported the Association. The IHA greatly appreciates the financial help given to the IHA by **The National Lottery**, Killiney Bridge Club and Castle Golf club.

The Media

Articles on HH have been published in the *Sunday Mirror*, the *Health and Living Supplement* of the *Independent*, the *Galway Advertiser*, the *Southern Star* and the *Medical News*. The *Afternoon Show* featured an interview with Meath footballer David Beggy and Dr Philip Mc Mahon.

Distribution of Brochures and Posters

The Transition Year pupils of St McCartans School in Monaghan assisted the IHA by organising the distribution of brochures to 2,200 GPs. More recently the IHA has employed a company called Inform to deliver the information material to the surgeries. In the coming months the IHA hopes to organise the distribution of brochures to all the **Public Libraries** and to the various **Pharmacies**.

Country: Germany

Speaker: Barbara Butzeck

The Haemochromatose-Vereinigung Deutschland HVD was founded in 2001 and grew little by little to actually almost 400 members. Barbara Butzeck, chairwoman of HVD presented the actions of the HVD between St.Gallen September 2008 and Porto June 2009. She explains the results of a fruitful first meeting with most of the medical advisors from different specialities like hepatology, rheumatology, genetics, transfusion medicine and the developing network of contact persons in the different counties of Germany. Photographs of a new information boot for representation on congresses was shown as well as the cover picture of a new 64 pages strong brochure in German called "Experts knowledge about hemochromatosis". At last she presents two examples of HH - patient's migration through Europe and the support EFAPH could give.

(Appendix 8)

Country: Hungary

Speaker: Judith Varkonyi



The Hungarian Hereditary Hemochromatosis (HH) patients association called: Hemokromatózisos Betegek Egyesülete (HBE) had been founded in 2006 and officially registered in 2008 and is a part of EFAPH.

According to the declaration document it has its assembly once in autumn and once in springtime; the last Friday of November and March regularly.

First time in Barcelona two of us had been participated just as observes and later as founders or initiators of HBE: Hajnalka Andrikovics PhD of laboratory sciences and me, Judit Várkonyi MD, Ph.D. Med.Habil. Hematologist at Semmelweis University, Budapest.

So far it calculates 10 active members attending these meetings and paying annual registration fee all together. Patient members had been gathered from those patients who belong to the 3rd Department of Internal Medicine Semmelweis University, where their

disease had been diagnosed and where they are cared for, being the “mother” institute of HBE.

Our regular meetings take place there upon the permission of Professor István Karádi who is the director of the institute. Experts on liver disease of other institutes who are most likely to meet first these patients- could not be gained so far to the matter and to send their patients for joining this civil association.

In the wish to widen the circle of those who might be involved however - other patients and their family members or doctors who potentially might diagnose the disease and might care for such patients – there was an increased publication activity in the field, and more and more lectures were given to GPs and to doctors participating at several courses like that of Blood Transfusion Therapy or for postgraduates in Hematology and for medical students.

Learning from the experiences of the latest Porto EFAPH meeting contacts had been searched and found in other institutes especially the leaders of genetic laboratories in the country. Upon this here data stand on how many patients had been diagnosed so far in Hungary: 61 in Pécs (in the laboratory of professor Béla Melegh DSc from 1999) and 11 in Budapest (in the laboratory of Zoltán Prohászka DSc from 2008). These data of the laboratory of Attila Tordai DSc Budapest and of professor Emőke Endreffy Szeged, and those of Debrecen will hopefully be also soon available.

On the regular meetings there is an introductory talk presented by the consultant on what new findings and therapy options are there in iron metabolism. There is a referral on the latest EFAPH meeting. The members might have- and they have - questions to the doctor and to a dietetic consultant and a friendly chatting – with changing experiences- enriches the meeting. As the doctor consultant of HBE is a hematologist special aspects of the disease are also reflected on the regular meetings, like how HFE gene mutation and hematological malignancies are related or what the relations are of copper deficiency and iron overload, etc.

One of the local Novartis representatives is usually participating at our meetings as well to give up to date information on the new chelator Exjade. From 2008 thankfully to Novartis the association has its own homepage www.hemokromatozis.hu

Future plans:

- Participating at the meetings of Hepatologists and Hematologists
- To open bank account for to give opportunity for those who would like to donate for our purposes, like to • pay registration fee and travel and accommodation expenses of regular meetings of hematologists and hepatologists, • to maintain and update homepage,
- advertise by all means the information on the disease by publishing annually a newsletter and other printed materials and organize family days for those who are involved with the invitation of famous people and representatives of health insurance company and the ministry of health. For all these matters it would be of great importance to employ at least one secretary and finance an office.

As in Hungary HH patients are not allowed yet for blood donation, it is our main goal to convince those at decision making to change their attitude to this matter. As liver cirrhosis is a frequent cause of morbidity and mortality in Hungary especially involved middle aged men, it is of utmost importance to screen the population for HH. For this purpose more activity is needed to make grant application in the wish to cover extra laboratory costs of liver function tests and to determine the iron parameters and that of the genetic analysis.

Country: Portugal
Speaker: Manuel Joao Costa

Manuel Joao Costa sent best regards from his father, the president of the Portuguese HH Association, who unfortunately could not be present because of his health condition. The Portuguese HH association has 70 members currently. A HH awareness day is planned for the 7th of June 2010. They are collecting signatures (need 3.000) for a petition to the Health Ministry.



Country: Norway
Speaker: Ketil Toska

Ketil Toska reported about the difficulties the Norwegian HH association has due to the global financial crises. Of the 7 board members, 5 have resigned and the number of paying members sank from 370 to 235 last year, especially old members cancelled. So the Norwegian HH association is in a phase of reformation. He advised that there are a few Patients from Sweden who joined the Norwegian HH-Association.



Country: France
Speaker: Jean Louis Balagayrie



The part of the FFAMH is first to create local associations close to patients and practitioners over the whole French territory.

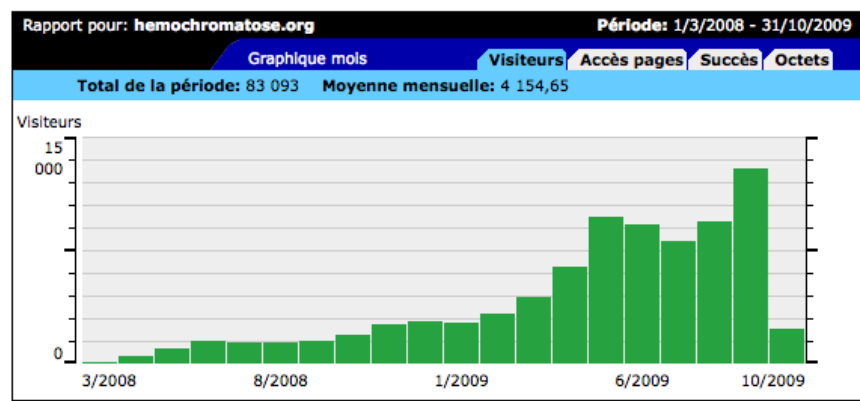
At the moment, there are four spots :

- Association Hémochromatose Ouest Bretagne (AHO)
- Association Hémochromatose Paris Ile de France (AHP)
- Association Hémochromatose Aquitaine (HAq)
- Association Hémochromatose Poitou Charente (HPC)

MULHOUSE & ORLEANS Associations are in process of being created, then LILLE, TOULOUSE, LYON, MARSEILLE will be the next sites ...

FFAMH takes actions on practitioners and institutions: In February, five of us participated to Conferences organised by EFS (French Blood Establishments) in PARIS and thus contributed to the plan of using blood samples extracted. Since April 2009 it has stopped been thrown away.

One brilliant succes of the year was the création and updating of our site, by Michel BOUDRY (MD). This constantly evolving site, visited in May 2009 more than 10000 times , allows us to keep a close link with patients, to answer to their calls and e-mails, giving them all informations concerning our & their deseases.



< <http://www.ffamh.hemochromatose.org/spip/> >

Our participation to EFAPH is mostly necessary, on our Continent, in order to harmonize the way to help our own members.

Country: Spain
Speaker: Albert Altes

Albert Altes apologized for not staying until the end of the meeting. Eddie Stark from Barcelona explained as spokesperson that the most relevant thing during the last year was the realization of a book in Spanish about haemochromatosis for physicians and for patients too. For the future it is planned to build a Spanish network of rare diseases related with iron together with Mayka Sanchez working in a laboratory about haemeochromatosis.

Discussion about HH awareness day

After the presentation of the international HH- associations the participants discussed the development of a cooperation or partnership of HH-Patients' organizations. It was recommended that such an International Alliance should also include the IBIS (International Bioiron Society).

National HH awareness days or months are already established in several countries between May and July. The audience agreed upon the first week in June 2010 as an international HH awareness week. Every national association is free to organize a day, weekend or week in its country during this time.

New Statutes

Speaker: Jacqueline Lassale and Francès Mullaney



New Statutes

Presentation of the new statutes (Version 8): a few details have been modified during the General Assembly and the definitive version was submitted. The final wording of these statutes was unanimously approved by the General Assembly.

(Appendix 9).

Elections: Administration Council and Executive Board

In accordance with the new statutes just approved, the Administration Council is now composed of 11 members, including 2 honorary founder members. It follows that only 9 seats had to be filled:

Founder members :

- Pr Pierre Brissot
- Jean Rialland

Members who did not want to run again

- Jean Rialland
- Pr Pierre Brissot
- Jacqueline Lassale
- Sophie Segaud
- Marie Bérengère Troadec
- Philippe Morillon
- Jean Paul Moisan

Resignation:

- Cok Dijkers (HV Netherlands)

List of the candidates:

- Albert Altès (Spain)
- Jean Louis Balagayrie (France)
- Barbara Butzeck (Germany)
- Manuel Costa (Portugal)
- Françoise Courtois (France)
- Frances Mullaney (Ireland)
- Graça Porto (Portugal)
- Ketil Toska (Norway)
- Judith Varkonyi (Hungary)

After a secret ballot, 22 people voted, and 9 candidates were elected (entire list).

The new Administration Council met and chose the 4 members of the **Executive Board**:

- **President : Barbara Butzeck**
- **Vice president :Frances Mullaney**
- **Treasurer: Ketil Toska**
- **General Secretary: Françoise Courtois.**

The Executive Board can nominate members of the Administration Council for specific missions.

With the election of a new presidency the official address of EFAPH has changed to:

EFAPH
Dr. Barbara Butzeck
Vidumestr. 23 A
D-45527 Hattingen
Germany

Barbara Butzeck thanked those present for the trust they have placed in her. She praised the work of the former board, in particular the creative directors Jean Rialland and Pierre Brissot and expressed her intention to build upon this work and to improvement the situation for all HH-Patients in Europe.



Conclusion



The General Assembly confirmed the change in chairmanship. Jean Rialland stays a rightful member as honorary chairman. Gratitude was expressed and a commemorative plate for his successful chairmanship was presented during the IBIS (Bio Iron) gala diner.

The time of the next General Assembly will be decided in accordance with the next annual EIC meeting.