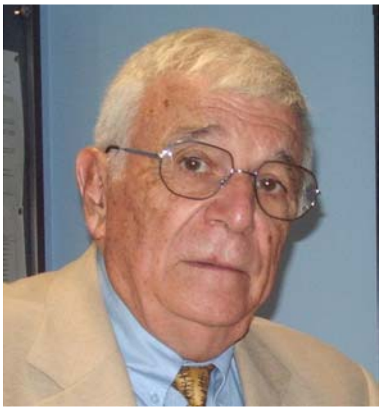
European Federation of Associations of Patients with Haemochromatosis
Fédération Européenne des Associations de Malades de l'Hémochromatose

Report of the third EFAPH Annual General Meeting

The meeting took place in Guy's Hospital, London, 16th of September 2007.

WELCOME AND INTRODUCTION



Speaker: **J Rialland, President**

In attendance:
Representatives of Hemochromatosis Associations for:
Germany (Barbara BUTZECK),
Spain (Albert ALTES),
France (Pierre BRISSOT, Françoise COURTOIS, Jacqueline LASSALE, Jean RIALLAND, Marie-Bérengère TROADEC),
United Kingdom (Stuart MACDONALD, Valerie HADFIELD),
The Netherlands (Philip DE STERKE),
Ireland (Frances MULLANEY, Margaret MULLET),
Norway (Sonia DISTANTE, Berit BORCH-IOHNSEN),
Portugal (Gracça PORTO).

Apologies:
Mr R. VAYN, president of FFAMH
Mr BALAGAYRIE, Vice-president of FFAMH
Mrs. S. SEGAUD, treasurer of EFAPH
General MORILLON, vice-president of EFAPH
Tanguy DE DECKER, president of the Belgium Hemochromatosis Association
Judith VARKONYI, president of the Hungarian Hemochromatosis Association
Jonsson HREGGVIOR, president of the Iceland Hemochromatosis Association
Rolf HULCRANTZ, president of the Swedisch Hemochromatosis Association
PIETRANGELLO Antenello, president of the Italian Hemochromatosis Association
KLINCEWICZ Pawel, president of the Polish Hemochromatosis Association

Part Attendance (Guests):
Mrs Susanna LETO DI PRIOLO, Responsible for relationship with patients Associations at Novartis Europe (Hemato-Oncology).
ANDY Jones (Novartis)
STARCK Eddie, representative of Spain Hemochromatosis Association
SANCHEZ Mayka (Spain)
RODDY Kate (UK)
KERR Briedgeen (UK)
CRICHTON Robert
Rob EVANS, Roberta WARD and Sebastien FARNAUD

The President of EFAPH, Jean Rialland, introduced the meeting by welcoming all present and thanked especially Rob Evans, Roberta Ward and Sebastien Farnaud for their kind assistance with the preparation of this meeting.

Board Meeting

The President of EFAPH, Jean Rialland, presented the moral and financial report.
The Administration Council approved it in order that it could be presented during the General Meeting.

MORAL REPORT
ONGOING ACTIONS

Speakers: **J Rialland and F Courtois**

See Powerpoint presentation below

EFAPH Representation at the European Union level

Since the end of 2006, EFAPH has been fortunate enough to have the use of an office in Brussels, kindly provided by the representative office of the Brittany region in France. This representation is very important because it gives EFAPH visibility at a European level. J Rialland and F Courtois use this office 2 days per month. A total of 16 days were spent in Brussels up to now and 3 dates are scheduled till the end of 2007. Many times B. Butzek (Germany) and F. Mullaney (Ireland) joined J Rialland and F Courtois in order to participle actively in the meetings.

This representation allowed them to contact many people working for the European Union.

Contacts

Contacts have been made with representatives of Slovenia, Malta and Romania with the aim of establishing National Haemochromatosis Associations in these countries.

Contacts have also been taken with Pr Danielle SONDAG THULL, Red cross Transfusion Belguim Director , Mrs Hildrun SUNDSETH Head of EU Policy – European Cancer Coalition, Dr Antonya PARVANOVA (MEP), European Deputy responsible for Health, Mrs Silvia OLTEANU , First secretary (Health) of the Romanian Representative office to the EU, Mr Philippe BRUNET, Head of Cabinet of Mr Markos KYPRIANOU - European Commissioner for Health and Consumer protection, Mrs Lysette TIDENS-ENGWIRDA – General Secretary of the Permanent Committee of European Doctors (CPME), Mrs Françoise GROSSETETE (MEP) European Deputy responsible for Health.

These contacts have facilitated in many positive actions for EFAPH and enabled EFAPH to raise awareness about haemochromatosis at a European level and to learn how to further raise awareness in an efficient way (see Projects section).

Actions

- Mr Jean Rialland and/or Dr F. Courtois participated in conferences in Rennes (France) about Europe, attended the colloque of Eurordis (European Federation of associations of Rare diseases) and were invited by the Rotary Club of La Baule (France) on the theme of Haemochromatosis (250 participants).
- F. Courtois prepared a survey on venesection management in EU.
- EFAPH also had the opportunity to present its activities and goals during the European Iron Club (September 2007, London).
- EFAPH is on schedule to becoming an active member of Eurordis (European Federation of associations of Rare diseases) and will attend the Eurordis Conference in Lisbon (Portugal), the 27-28 november 2007.
- An information leaflet (in English, French and German) will shortly be available for all EFAPH members as a new means of communication. During the meeting, the first page of the leaflet was discussed (mainly the colour of the European map). Philip de Sterke kindly proposes to submit further comments by email. Final versions will be circulated to all members for comment.

Projects on going:

- To assist the EFAPH members with any information-prevention actions
- To approach the Health Authorities of the 15 countries not registered with EFAPH
- To approach the media dealing with Europe (*suggestion: The European Voice, a newspaper in Brussels)*
- To homogenize the clinical practice and treatment of haemochromatosis across Europe.

- To participate in FP7 (7th Framework Research program) of the European Union.
- To promote information campaigns of General Practitioners. A letter coordinated by B Butzeck, was approved during this meeting and following further comments will be sent to the Permanent Committee of European Doctors (CPME)
- To create a news bulletin
- To promote creation of Competence Centres at all national levels.
- To promote research projects
- To prepare a presentation of EFAPH with Mrs Grossetete for the meeting scheduled with the European deputies for Health in the European Parliament in December.

Sponsorship

EFAPH is sponsorized by Novartis for well-defined actions (including the organization of the Annual General Assembly).

Membership

EFAPH is member of EURORDIS

Vote of the board and Election of the President

The former members of the administration Council proposed their application. No new applications were proposed. The administration Council was then renewed, and re-elected and Jean Rialland was re elected as the President of EFAPH.

Application of Iceland

Iceland hemochromatosis Association proposed its application 6 months ago. A vote has been taken place by email in order to officially approve Iceland as a full member of EFPAH.

FINANCIAL REPORT

See Powerpoint presentation below

Decisions:

-Send member fee (1Euro/member) on time: deadline 30 March of each year
-Creation of a committee of control of the finance (see page 9)

ACTIVITY REPORT & PROJECTS by NATIONAL ASSOCIATIONS

Country: Ireland
Speaker: Margaret Mullet

The Irish Haemochromatosis Association started in 1995 and the main aim is to raise awareness and support newly diagnosed patients. Recently there has been a great increase in the membership and there are well over 950 people on the database, including some nurses and doctors, however approximately 450 are actually paying members.
In June 2006 a report on HH was given to the Minister for Health. This report examined all the issues relating to Haemochromatosis in Ireland and listed several recommendations that the IHA would like to see implemented. The IHA advised the Minister on the actions necessary to address these issues. Some progress has been made but there is still a lot of work to be done.

The Board of the IHA consists of 7 members and meets at least four times a year .The AGM takes place every year in Dublin, usually in May.
A Newsletter is sent to the members 3/4 times a year and when possible calls and queries from patients are answered on a daily basis.

Ireland's First Haemochromatosis Blood donations
The first blood donation from HH patients in Ireland has taken place at the Irish Blood Transfusion Services blood donation clinic in Stillorgan, Dublin, marking the beginning of a year long pilot study.

Information Meetings
Last year a series of successful information meetings were held throughout the country in: Sligo, Clonmel, Wexford, Cavan and Limerick**.** Thanks to the doctors and nurses who gave of their time to speak at these meetings.The meetings were advertised on local radio and in regional newspapers. This year a further 6 meetings are being organised and again the media coverage is a great help in raising awareness.

Regional Support Meetings
Midwestern Haemochromatosis Support Group (MWHSG)
This group includes Limerick City and County, North Kerry, Clare and North Tipperary. This group has had several successful meetings and deals with issues that are particular to that area.

National Ploughing Championship
The IHA will man a stand for three days in September at this meeting and will distribute brochures and posters to the thousands of farmers who will attend.

Donations and Fundraising

Last year the **Women's** mini Marathon raised a grand total of almost €8,000.

Distribution of Brochures to General Practioners

Brochures, a poster and a venesection record card were distributed to 2,200 GP'S.
This year it is planned to include a copy of the handbook in the information being sent to the GP's.

Irish Handbook on Haemochromatosis

The Irish Haemochromatosis Association has completed an updated version of the Australian hand book. This booklet is available to members and has been sent to every member.

Country: Portugal
Speaker: Graça Porto

This association was created 3 years ago. There are 50 members which meet every month. They propose information, practical support for patients and would like to approach the Health authorities.

Country: Spain
Speaker: Albert Altes

There are 120 members. A particular effort was done this year for the web page. They edited a manual given to the members. They have the project of a blood bank in Barcelona, and would like to receive funding from the Ministry of health.

Country: France
Speaker: Françoise Courtois

Details were given of the many projects currently being undertaken by the recently formed French Association including a brochure, a newsletter and a venesection record booklet passport. This association are working to develop new regional branches of the association.

Country:The Netherlands
Speaker: Philip De Sterke

The Netherlands hemochromatosis association is very active with many actions underway giving information to HH patients (Book, newsletters, information meetings…), collaboration with the clinic and research Centre in Nijmegen, and the promotion of research (eg HEFAS study).

Country: Norway
Speaker: Sonia Distante

See Powerpoint presentation below

Country: Germany
Speaker: Barbara Butzeck

See Powerpoint presentation below

Country: UK
Speaker: Stuart Mc Donald

See Powerpoint presentation below
The Haemochromatosis Society presented us the results of a questionnaire including data on Symptoms, Age at which symptoms Developed, Age at diagnosis, Lifestyle effects, Treatment duration (mins), GP's knowledge, etc. This data is very interesting because it reflects the practices in UK.

LECTURES

THE HFE GENE: A CELTIC STORY?

Speaker: P Brissot

Professor P. Brissot addressed the question of the celtic origin of the C282Y HFE mutation. His talk began with a short definition of the Celts. It is not a race, but mostly a population sharing the same language, and which spread from the deep Alps to Western Europe, North Spain, Portugal and Italy from -1500 to -400 BC. It was proposed in 2000 that the mutation appeared about -2000-3000 years BC. However a more recent publication (S. Distante et al, Human Genetics, 2004) demonstrated that the mutation appeared before 4000 BC. Professor P. Brissot then presented a complete history of the studies comparing haemochromatosis spread and the pattern of Celt migration. At the end of this presentation, the hypothesis of Viking origin of the C282Y HFE mutation was discussed. The conclusion of this well illustrated talk was as follows: the Haemochromatosis gene is most probably of celtic origin, Celts have been the great propagators of the gene, and finally, Vikings have certainly contributed to this propagation.

COMPARISON STUDY OF VENESECTION MANAGEMENT WITHIN EUROPE: RESULTS OF A QUESTIONNAIRE

Speaker: F Courtois

See Powerpoint presentation below

EUROPEAN PROJECT ON VENESECTION THERAPY AND QUALITY OF LIFE: PRESENTATION AND DISCUSSION

Speaker: S. Leto di Priolo

S. Leto di Priolo, Head of Patient Advocacy Relations Novartis Oncology Region Europe, presented the European project on venesection therapy and quality of life. The aim of this study is to:

- Understand how patients with haemochromatosis cope with the condition and the burden of the disease and its treatment on their daily life
- Evaluate the patients' level of satisfaction with phlebotomy
- Understand the patients' needs in terms of treatment
- Explore their views and level of interest in receiving oral treatment for haemochromatosis.

FERRITIN AND TRANSFERRIN SATURATION: WHICH LEVELS DURING MAINTENANCE THERAPY?

Speaker: P de Sterke et al

Mr. Philip de Sterke spoke on the topic of the management of phlebotomy regarding the ferritin and transferrin saturation parameters. The criteria seem to vary in many countries and is not clearly defined, and depends on where the treatment is undertaken. Mr. de Sterke believes that specific research in this area needs to be undertaken. Professor P. Brissot recalls that, up to now, the main parameter to look out for is a low serum ferritin irregardless of the transferrin saturation. However, transferrin saturation is important for the diagnosis of the disease.

QUESTIONS/PROPOSALS DURING THE GENERAL ASSEMBLY

OPERATION OF THE FEDERATION

Creation of a committee of financial control

Improve transparency and forward planning
Three volunteers: Valerie HADFIELD, Philip DE STERKE and ?
Voted by unanimity

Creation of Internal Rules

It has been proposed to amend the statutes so that it will now state that there must be a minimum number of patient representatives in both the national associations and EFAPH. A proposal will be sent by email.

Issue of the agreement before sponsorship and participation of commercial company

It has been decided that the agreement of the majority of the National Associations will be required prior to any engagement with a commercial company from now on.

Improvement of the exchange of data within the members of EFAPH

Philip De Sterke proposes to create a collaborative platform via Internet (like a Wiki) for EFAPH members. This proposal has been sent to you by email.

INFORMATION OF PATIENTS AND GP

European guidelines for phlebotomy

It appears that there are no clinical practice guidelines for phlebotomy for the management of Haemochromatosis in Europe. Such a document exists in France (http://www.has-sante.fr/), but it could be a goal for EFAPH to produce such a document at European level.

Collection of the newsletters of the National Associations

It has been suggested to circulate each of the member newsletters to all EFAPH members to enhance the awareness amongst all pf what is being undertaken in each country.

Improvement of the Web site

Mainly change the first page to become more informative
To put available documents as guidelines, the result of the survey about venesection management within Europe, etc.

Initiate Competence Centres

We know that competence centres exist in some European countries but not all. EFAPH will try to raise awareness about this and encourages each EFAPH member to do likewise in their own country.

We look forward to welcoming you to the next General Assembly Meeting of EFAPH in Saint Gallen (Switzerland), 20th of September 2008.

GENERAL ASSEMBLY

LONDON
SEPTEMBER 16, 2007
King’s College London, Waterloo Campus

SUMMARY

1. Representation in Brussels
2. Contacts
3. Concrete actions
4. Federation Overview
5. Projects
6. Partners

---

1 – Office in Brussels

At the end of 2006, EFAPH were fortunate enough to take up temporary residence in the offices of the represenatative office of Brittany (French region) to the EU in the centre of Brussels.

This allows EFAPH to be present in the heart of the political centre of Brussels two days per month. EFAPH is represented here by Jean RIALLAND, President of EFAPH and Dr. Françoise COURTOIS – Technical Advisor to EFAPH.

---

1 – Office in Brussels (Contd.)

AGENDA

20 & 21 December 2006
23 & 24 January 2007
27 & 28 February 2007
15 & 16 March 2007
18 & 19 April 2007
22 & 23 May 2007
05 & 06 June 2007
16 & 17 July 2007

This gives a total of 16 full days in Brussels raising awareness about Haemochromatosis and EFAPH at a European level.

Future Provisional Calendar:

3 & 4 October 2007 - 20 & 21 November 2007 - 18 & 19 December 2007

---

2 – Contacts

The physical presence of EFAPH on the ground in Brussels has facilitated numerous important contacts to be made by meetings in person and by phone with National Member State offices in Brussels, with Members of the European Parliament, with the European Commission and with many contacts that could enable us to encourage those countries who are currently not members of EFAPH to join.

This is one of the aims of EFAPH to grow its membership by establishing structures in countries where none currently exist. EFAPH will try and provide support, technical assistance and share best practice to these countries such as:

- Slovenia
- Malta
- Romania

---

2 – CONTACTS (Contd)

Each of the important meetings with the European Representatives from the European Commission and the European Parliament and other patient representative groups were selected according to their relevance to the area of work of EFAPH.

These meetings have enabled EFAPH to raise awareness about its existence and raise awareness about the gentic disorder of Haemochromatosis. EFAPH presented its’ goals :

2 - CONTACTS (Contd)

- Général Philippe MORILLON – Member of the European Parliament (MEP) – France – January 2007
- Pr Danielle SONDAG THULL – Directrice of the Red Cross (Blood transfusions, Belgium) – March 2007
- Mrs. Hildrun SUNDSETH Head of EU Policy – European Cancer Coalition - May 2007
- Dr Antonya PARVANOVA – Member of the European Parliament (MEP) (ALDE (Liberal Health Coordinator) - Bulgaria - May 2007

2 - CONTACTS (Contd)

- Mrs Silvia OLTEANU – First Secretary of the Permanent Representative Office of Romania to the European Union - June 2007
- M. Philippe BRUNET – Head of Cabinet of Markos KYPRIANOU – Commission for Health & Consumer Protection - July 2007
- Mme Lysette TIDENS-ENGWIRDA – Secretary General- of teh Standing Committee of European Doctors (CPME) - July 2007
- Madame Françoise GROSSETETE – Member of the European Parliament (MEP) (Health Coordinator of the EPP Group) – January 2007

3 – CONCRETE ACTIONS -

EFAPH partook in two conferences on the subject of the Europe. EFAPH used these conferences as an opportunity to raise awareness about EFAPH and haemochromatosis:

- Rennes : "Europe" - Espace Ouest-France
  5 December 2006
- Rennes : « Finland " - Espace Ouest-France
  13 December 2006

3 - CONCRETE ACTIONS (Contd.)

- EFAPH ran an information meeting on haemochromatosis in conjunction with the International Rotary Club on the theme of haemochromatosis in the region of La Baule (France) 16 April 2007
- Paris : EURORDIS Colloquium 4 & 5 May 2007

3 - CONCRETE ACTIONS (Contd.)

- Survey of European Practices on the treatment of haemochromatosis: treatment, costs (March 2007 – results presented in London September 2007)
- Oral Presentations at the European Iron Congress (European Iron Club, London, 13 - 15 September 2007 - Poster)
- Preparation of dossier to become an active member of EURORDIS (attendance at the Conference on rare diseases Lisbon, 27 & 28 November 2007)

3 - CONCRETE ACTIONS (Contd.)

Development of support material:

1. A public information sheet about prevention.

   A sample will be presented at the General Assembly in London. This can then be replicated by the national members in their own language for use at the Member State level.

2. A two sided leaflet presenting EFAPH to be used for communication and information purposes, in french and english.

4 – Federation Over

A - Administration :

- Administrative Council before the General Assembly 27 September 2006 – Barcelona – Spain
- General Assembly 27 September 2006 – Barcelona – Spain

---

4 - Federation Overview (Contd.)

A - Administration Contd. :

- Meetings of the Secretariat (3 meetings) :
  4 December 2006 - 5 February 2007 - 19 March 2007
- Work Coordination Meetings (4 meetings) :
  5 April 2007 - 12 June 2007 - 31 August 2007 - 10 September 2007

---

4 - Federation Overview (Contd.)

B - Concertation :

- Meetings regarding the representative office of Brittany in Brussels - Rennes - 22 December 2006 et 12 July 2007 with Mr. Jean-Yves LE DRIAN - President – to discuss EFAPH's presence in these offices in Brussels
- A technical meeting 12 January 2007 to set up the european contract between Professeur BRISSOT's team from Pontchaillou, Rennes and the European Commission (DG SANCO) concerning research in the area of iron related disorders across the European Union.

---

5 – PROJECTS

- To help and support the creation of iron-overload prevention campaigns in the member countries of EFAPH
- To approach the health authorities and/or the patient associations of the 15 european countries that are not yet members of EFAPH
- To make contact with European media (TV, newspapers, radio,etc.…)
- To seek to harmonize practices across Europe

---

5 - PROJECTS (Contd.)

- To participate in FP7 (Health Research Projects) – a dossier will be compiled in Spring 2008 to request funding
- To promote European Information Campaigns to raise awareness amongst the european Medical profession (in partnership with CPME - Comité Permanent des Médecins Européens / Standing Committee of European Doctors)
- To promote european information campaigns to educate the various institutions
- To create a European Newsletter

---

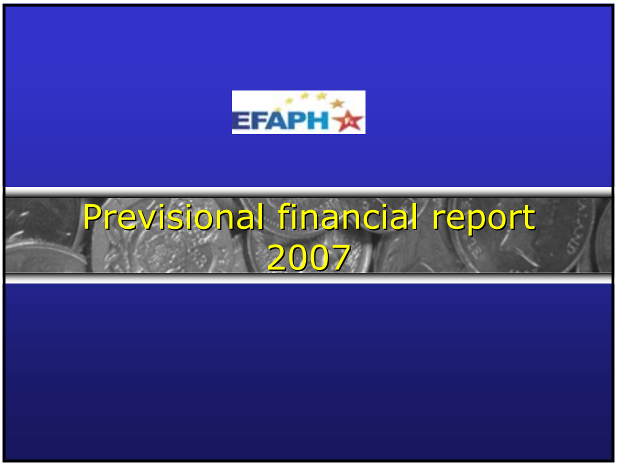
5 - PROJECTS (Contd.)

- To promote the establishment of Reference centres for haemochromatosis throughout the EU, similar to the one in place at Rennes (France) under Professeur Brissot's team (September 2007)
- To promote Research programmes (project NOVARTIS…)
- To host an event (before the end of 2007) with Mdme. GROSSETETE (MEP) as sponsor given her role as health spokesperson for the EPP group in the European Parliament.

6 – Partners

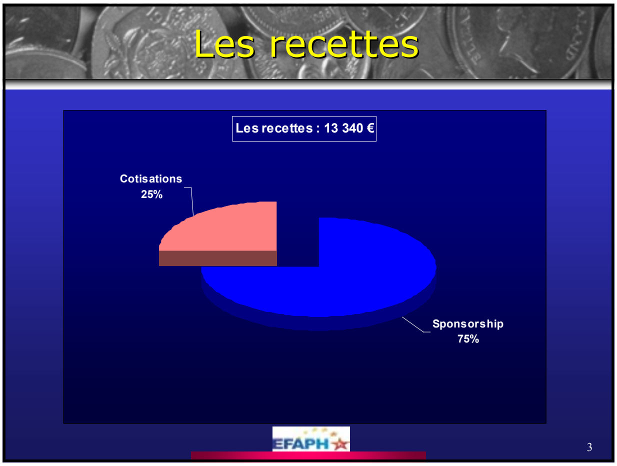
- Membership: EURORDIS
- Sponsorship:The NOVARTIS laboratory

EFAPH has received financial support (in particular for the organisation of the General Assembly each year) from Novartis

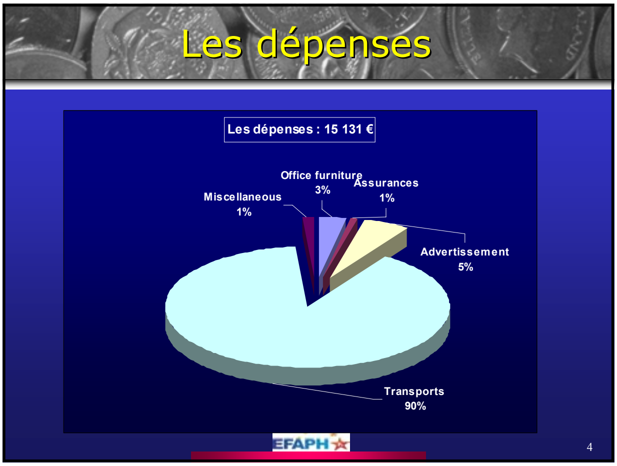


Previsional financial report 2007

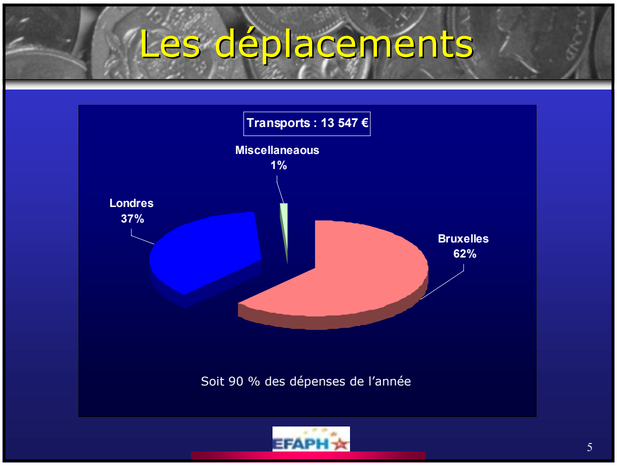
Sommaire



Les recettes

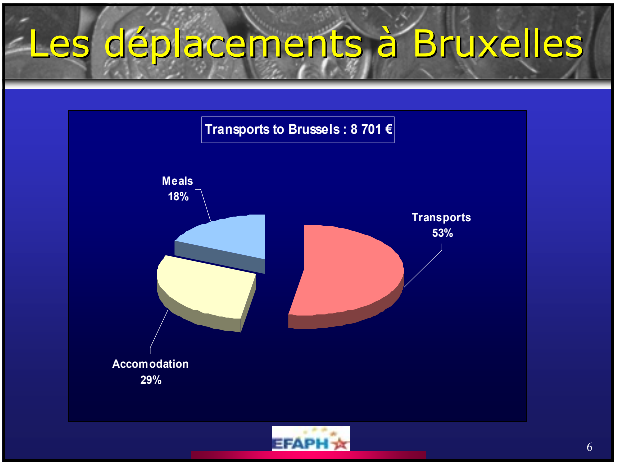


Les dépenses



Les déplacements

Soit 90 % des dépenses de l'année



Les déplacements à Bruxelles

Résultat prévisionnel 2007

Results of the year

	2007	2006
Recettes	**13 340**	**13 486**
Dépenses	**15 131**	**4 955**
Résultat	**- 1 791**	**+ 8 531**

Bilan prévisionnel 2007

Bilan prévisionnel

ACTIF	MONTANT	PASSIF	MONTANT
SOCIETE GENERALE **(compte sur livret)**	**106.58**	Report à nouveau 2006 (excèdent)	8 531.54
SOCIETE GENERALE **(compte courant)**	**54.81**	Résultat de l'exercice 2007 (déficit)	- 1 790.57
Clients	**10 000.00**	**Report à nouveau 2007 (excèdent)**	**6 740.97**
Débiteurs et créditeurs divers **Produits à recevoir**	**1 879.00**	**Fournisseurs**	**850.00**
Charges constatées d'avance	**550.58**	**Débiteurs et créditeurs divers** **Charges à payer**	**5 000.00**
TOTAL ACTIF	12 590.97	TOTAL PASSIF	12 590.97

QUELLES SOLUTIONS POUR 2008 ?

Activity report and projects

Norvegian Haemochromatosis Association

Sonia Distante, M.D., Ph.D.
representative

Norvegian Haemochromatosis Association (NHA)

- Established 18 mai 1999
- 314 members (dec. 2006) (4,5mill Norway), select representative to a general assembly
- One national meeting and 4 board meetings per year.
- Board consists of 5 members and 2 extras.
- NHA is authorised to represent patients with hemochromatosis and receives yearly economic support from goverment.

Norvegian Haemochromatosis Association (NHA) Aims:

- Distribute information on haemochromatosis: leaflets, media, internet, conferences (Bergen 2007), patient councelling.
- Collect information: sponsoring of research projects
- Influence health organisations to a greater awareness on Haemochromatosis
- Achieve early diagnosis of haemochromatosis at least before complications have occurred.
- Support haemochromatosis patients

Norvegian Haemochromatosis Association (NHA) Strategy:

- Create awareness of hemochromatosis, www.hemokromatose.no
- Introduce routines for measurament of transferrin saturation among adults (>20years)
- Develop screening methods, organise economy for screening

Norvegian Haemochromatosis Association (NHA)

NHA established the Norvegian Centre of Competence on Haemochromatosis (2004 in Oslo, now in Bergen).

Medical doctors with a specific interest in haemochromatosis meet regularly.

Aim of the Competence Centre:

- Exchange of information (Internet site)
- Contact with other national health and political bodies

Norvegian Haemochromatosis Association (NHA)

- EFAPH (European Federation of Associations of Patients with Haemochromatosis),
- (Since 2005, umbrella organisation includes 8 European countries)
- Support research and information
- Influence political and health bodies on a European scale for the interest of patients

Norvegian Haemochromatosis Association (NHA)

- Research …..

- Aamodt AH. Prevalence of haemochromatosis (HFE) gene mutations in Parkinson's disease. J Neurol Neurosurg Psychiatry 2007; 78:315-7
- Åsberg A, Hveem K. Penetrance of the C28Y/C282Y genotype of the *HFE* gene. Scand J Gastroenterol 2007;42:1073-7.
- Åsberg A. Prevalence of liver fibrosis and cirrhosis in screening-detected C282Y homozygous. Scand J Gasteroenterol 2007;42:782-3.

Norvegian Haemochromatosis Association (NHA)

- Research …..

- Åsberg A. Arvelig hemokromatose - nytten av screening. Norsk Epidemiologi 2006;16:23-8.
- Thorstensen K. Transferrin saturation should not be corrected for body mass index in screening studies for haemochromatosis. J Hepatol 2006;44:1003-4.
- Broderstad AR, Serum levels of iron in Sor-Varanger, Northern Norway - an iron mining municipality. Int J Circumpolar Health 2006;65:432-42.
- Distante S. Genetic predisposition to iron overload: prevalence and phenotypic expression of hemochromatosis-associated HFE-C282Y gene mutation. Scand J Clin Lab Invest 2006;66:83-100.

Report Hämochromatose-Vereinigung Deutschland HVD

(German HC-Association)

Dr. med. Barbara Butzeck, HVD
EFAPH, 3rd General Meeting
September 16th 2007
Waterloo Campus Kings College London

Topics

- Organisation HVD
- Activities last year
- Contact to politicians and authorities
- comments about EFAPH working group Brussels with suggestions

250 HVD-members

1/2007

HVD board

- Barbara Butzeck, president
- Mario Haub, vice-president
- Wilfried Horstmann, treasurer
- Renate Fritsch, public relations
- Annemarie Kreis, member affaires

Regional contact persons

HVD board and contact persons

Regional HVD contact persons
2nd Annual Meeting
10.March 2007, Schloß Gymnich

Topics

- Improvement of Public awareness
- HC-Therapy: costs, blood donation
- Psychological burden of advisors in support groups

Schloß Gymnich

Regional HVD contact persons
2nd Annual Meeting
10.March 2007, Schloß Gymnich

Topics

- Improvement of Public awareness
- HC-Therapy: costs, blood donation
- Psychological burden of advisors in support groups

Experts, Scientific board

- Prof.Claus Niederau, Oberhausen
- PD Dr.Dr.Peter Nielsen, Hamburg
- Prof.Wolfgang Stremmel, Heidelberg
- PD.Dr.Sven Gehrke, Baden-Baden
- Prof. Manfred Stuhrmann-Spangenberg, Hannover
- Dr. Angela Schabel, Stuttgart
- Dr. Sabine Hentze, Heidelberg
- Dr. Jochen Zwerina, Erlangen

German HC-Experts

Activities

- Information evenings / days for patients
- Presentation on congresses and health fares
- Cooperation with universitiy clinics for research

Information events for patients – Meetings

- October 2006 Bonn: universitiy clinic, Dept. Hepatol. Presentation of Fibroscan, examination of HC-Pat.
- December 2006 Cologne:
  Topic: sexual disorders in men with HC
- March 2007 Cologne: Annual General Meeting
  lecture Prof. Claus Niederau
- April '07 Siegen: Weekend workshop
  subject: joint pain in HC
- August '07 Cologne: Talk PD Peter Nielsen
  subject: News from Bioiron, Kyoto
- September '07 Edesheim (south-west)
  speech: Prof. Claus Niederau
- October '07 Halle/Saale (east): Regional meeting
- November '07 Cologne:
  speaker Prof. Mödder, topic: radiosynorviothesis

Presentation on congresses and health fares

- September 2006: Potsdam
  Annual meeting of general practioners
- October 2006: Wiesbaden
  German congress for Rheumotoloy
- February: Leipzig health fare
- March: Herner Lebertag
- May: Frankfurt-Main Selbsthilfetag
  Dessau Middle German GE congress
- September: Bochum DGVS
- October: Nürnberg Bavarian GE congress

Cooperation with universitiy clinics

Clinical Studies:

- 10/ 2006 Universitiy of Bonn
  Identification of gene factors in developing liverfibrosis
- 12 / 2006 Intern. study iron chelator Exjade Novartis
  three study-centres in Germany
- 2007 observation study HC-Arthropathy
  Universitiy of Erlangen, Dept. Rheumotology

Education of medical students:
Contact to faculties for human genetics with presentation of HC-Patients in the lectures

Contact of HVD to politicians and authorities

Rare so far
- mainly to medical associations and institutions, red cross, health insurances

- attempt to get in contact with German EU-deputies not sucessfull so far

◆ Argument contra :
Politicians are temporary elected

◆ Argument pro:
experience in EFAPH working group in Brussels

Suggestions to the EFAPH community

◆ To put medical information on our website

◆ To put more information about the activities of the national associations on the website of EFAPH
- in the origin language –

◆ Create a CD or DVD to educate the public about HC

Thank you for your attention

Barbara Butzeck, HVD

United Kingdom

The Haemochromatosis Society

- 5 Directors
    - Janet Fernau
    - Valerie Hatfield
    - Kit Farrow
    - Kate Roddy
    - Stuart McDonald
- Approx 1000 members
- www.haemochromatosis.org.uk

Activities

- Provide a support helpline
    - Handbook and support leaflets
- Monthly newsletter
- Annual general meeting
    - 2 or more regional meetings
    - 4 director meetings
- Provide funding for research
- Provide funding for awareness
- Detailed questionnaire

Comparative study of venesection management within Europe: Results of a questionnaire

London september 16 2007
Waterloo Campus of King's College London – 3th EFAPH Annual meeting

Françoise Courtois (Technical Councillor EFAPH) - **Barbara Butzeck** (vice président EFAPH Germany)

AIMS

1. To draw up a European survey in 2007 regarding the handling of the following topics:
    - phlebotomies
    - usual costs
    - Disposal of removed blood
2. To carry out a common reflexion (EFAPH)
3. To make suggestions regarding a possible standardization of the different practices

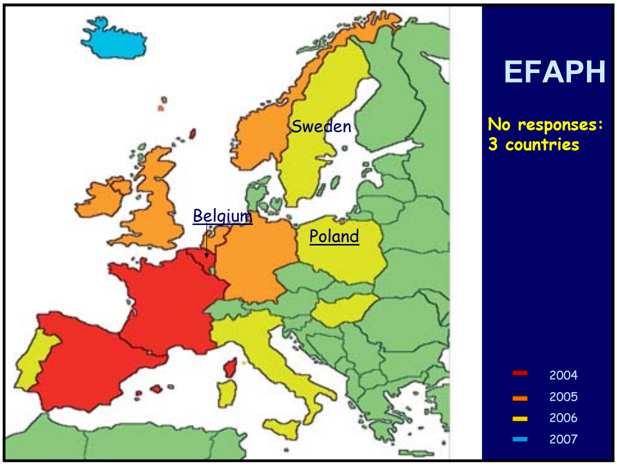
---

Methodology

- Survey produced by an EFAPH working group and addressed (March 2007) to the presidents of the 14 countries of the EFAPH
- It contained 6 topics:
    - Where the phlebotomies are performed
    - Existence - or not- of a medical check-up before each phlebotomy
    - Usual costs for phlebotomy
    - The technique of erythrocytapheresis
    - The quantification of the blood volume taken at each phlebotomy
    - Use / disposal of removed blood

General results

- 14 countries investigated
- 11 responses for:
    - Whole country: 10
    - Only 1 region: North of Portugal



No responses: 3 countries

---

(1) Where does the treatment usually take place?

- <u>In an hospital</u>: 10 / 11
    - 100% in a hospital: Spain, UK
    - Partially in a hospital: Ireland, Iceland, France, Hungary, Nederland, Portugal, Norway
    - Rarely in a hospital: Germany
    - Never in a hospital: Italy
  - ***In a day hospital*** : 70% (forbidden in France: guidelines 2005)
- *In a medical practioner's office* : 4/10 countries (in Germany > 80% of phlebotomies)

- *Ambulatory process (polyclinics…)* : 4/10 countries
- *In a blood transfusion center* : 6/10 countries
    - 100% in a blood transfusion center : Italy
    - 50% in a blood transfusion center: France, Portugal
- *By a mobile nursing unit:* 1 country (France: rare)

(2) A medical check up before each phlebotomy?

- No check up : 1/11 (Iceland)
- Only biology: 6/11
  - Heterogenous practicals:
    - only Hb,
    - ferritin and blood count…
- Medical consultation and +/- biology: 4/11

---

(3) Cost and phlebotomy…

	Countries (N)	
Free	3	Spain, Portugal, UK
Homogenous costs in the whole country	4	Hungary 4 € Norway 13 -> 15€ (free > 10 phl) Italy 44 €
Heterogenous costs in the whole country	5	France 14.77 -> ??? variable Nederland 75 -> 300 € Iceland 700 ISK -> 5000 ISK Germany 15 -> 150 € Ireland free to 600 €

---

(4) Cell apheresis as an alternative treatment?

Yes	5 Spain, Germany, France, Italy, Nederland (1 trial…)
No	6

---

(5) Is the volume of blood removed quantified?

Yes, by a specific device	8
Variable	1
No	2 Spain, Iceland

---

(6) Is blood removed used for transfusion?

Yes	0
Variable in the country	4 Germany, Portugal, UK, Norway
No	7 France (national guidelines 2005), Spain, Nederland, Hungary, Italy, Iceland, Ireland

---

(7) Is blood removed used for research?

Yes, variable	7
No	3
No response	1

(8) Is blood removed used for quality controls?

No	5
Variable	5
No response	1

(9) Is blood disposed of with hygienic rules?

Yes	6
No	1 (UK)
Variable	2 (Germany, Ireland)
No response	2

Conclusions (I)

1. In all countries (except Italy) the phlebotomies can be performed in a hospital and <u>70 % of the countries offer a treatment in day-hospitals</u>

   In two-thirds of the countries the phlebotomies take place in a Blood Transfusion Center <u>(Italy:100%)</u>

   In 4 of 10 countries the phlebotomies were performed in a medical practioner's office or in a clinic (ambulatory process)

   Only <u>1 country has a mobile nursing unit</u>

Conclusions (II)

2. <u>The check-up before each phlebotomy</u> is done in one third of the countries both under a medical and a biological point of view ; in two thirds of the countries only the biological side is checked but the methods are very different. And only one country (Iceland) does not control systematically.

→ <u>A future EFAPH discussion?</u>

Conclusions (III)

3. In 75% of the countries blood removal is well quantified; two countries use venesection device without the possibility of quantification (Spain, Iceland)

   → <u>A future EFAPH discussion?</u>

Conclusions (III)

3. In 75% of the countries blood removal is well quantified; two countries use venesection device without the possibility of quantification (Spain, Iceland)

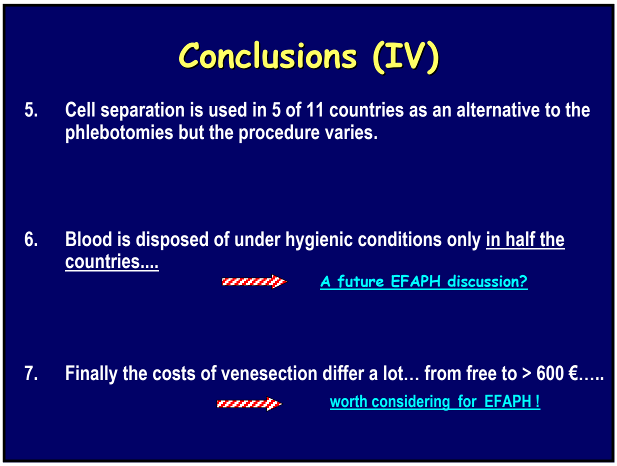
   → <u>A future EFAPH discussion?</u>

4. The removed blood is used :
   - For transfusion in 35% of the countries and with variability in the remaining 6 countries

     → . *EIC poster n° 20**
       . <u>*A new EFAPH discussion?*</u>

   - In different ways for research (63%) or for quality controls (50%)

** **Jolivet-Gougeon and al:** Serum transferrine saturation increase is associated with serum bactericidy decrease in patients with HFE related genetic hemochromatosis*



Conclusions (IV)

5. Cell separation is used in 5 of 11 countries as an alternative to the phlebotomies but the procedure varies.

6. Blood is disposed of under hygienic conditions only in half the countries….

   → A future EFAPH discussion?

7. Finally the costs of venesection differ a lot… from free to > 600 €…..

   → worth considering for EFAPH !

Thank you !

and…

The discussions are open!…