



# 2<sup>nd</sup> Survey on HH-treatment (July 2010)

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# *Outline*

1. *Aims*

2. *Methodology*

3. *Results*

4. *Conclusions*

# AIMS

1. Reiterate the survey on HH treatment and compare the results with those presented in 2007 in London with the same topics:
  - phlebotomies
  - usual costs
  - disposal of removed blood
2. Highlight topics which arouse a discussion with EFAPH members and in consequence to create some working groups in 2011

# Methodology

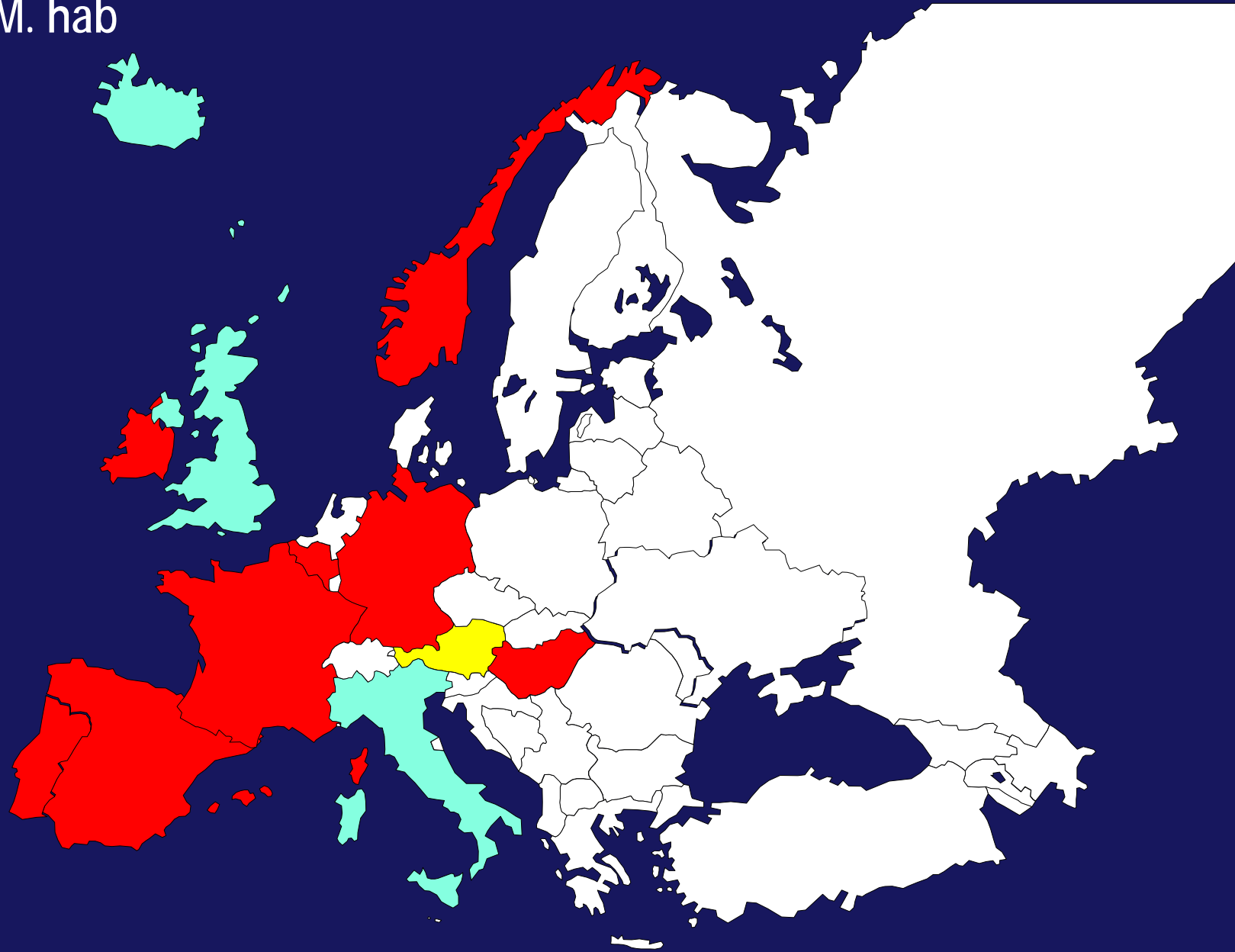
- May 2010: review of the 1st questionnaire, 6 topics were retained (few modifications)
- June 2010: the questionnaire was dispatched to the presidents of 11 EFAPH members + 1 country not yet in EFAPH (Austria)
- September 2010: feedback and analysis

# General results

- 12 countries investigated
- 8 responses for:
  - “Whole” country: 3
  - Part of the country : 5

8 countries

214 M. hab



	Inhab. (millions)	App. survey coverage (%)
Germany	82	100
Norway	5	100
Spain	39	100
Hungary	10	75
Ireland	4	75
Belgium	10	50
France	58	50
Portugal	10	25
<b>TOTAL</b>	<b>218</b>	

\* Approximately 60.000 HFE 282Y/282Y

# (1) Where does the treatment usually take place?

- 100% in an hospital (Day hospital): 1/8 countries (Spain)
- 100 % in a Blood Center : 1/8 countries (Hungary)
- Several locations :
  - Day hospital + Blood center : 2/8 countries (Belgium, Portugal)
  - Hospital + Blood center: 1/8 countries (Norway)
  - Day hospital + Blood center + gen. practionner 2/8 countries (Germany, Ireland)
  - Hospital + Blood center + mobile nursing unit (at home) and nursing center + Medical laboratories... } 1/8 countries (France)



# Check up (consultation) before phlebotomy

	Each time	Variable	No response
Medical practionner		2 Hungary, Spain	
Nurse		2 Portugal, Belgium	
Med.Pract + Nurse	1 France	1 Germany	
Not specified		1 Norway	1 Ireland

# Biological ckeck-up before each phlebotomy?

	No response	Each time	Variable frequency	Seldom
Hb		6	2 Belgium, Spain	
Only Ferritin	1 Spain	1 Ireland	6	
Fer + Trf sat	3 Belgian, France Ireland		4 Portugal, Hungary, Norway, Spain	1 Germany

### (3) Phlebotomy cost for patients...

	Countries (N)	
Free	4	Spain, Portugal, Germany, Hungary
Heterogenous costs	4	France 14.77 € -> ??? variable Ireland free -> 750 € Norway free -> 38 € Belgium free -> 3 €

## (4) Cell apheresis as an alternative treatment?

Yes but occasionally	5 Germany, France, Hungary, Norway, Belgium
No	1 Ireland
No response	2 Portugal, Spain

## (5) Is the volume of blood removed quantified?

		Adapted?	Not every time
No	1 Spain		
Yes	7	5 France, Belgium, Portugal, Hungary, Ireland)	2 Germany, Norway



*The interpretation of the answers was difficult because of a misunderstanding in the question*

## (6) Is blood removed used for transfusion?

Yes	2 France, Portugal
Variable in the country	3 Germany, Ireland, Norway
No (but probably a national issue)	3 Hungary, Belgium, Spain

# Conclusions (I)

## 1. Take the results with precaution:

- The answers reflect mainly the presidents' experiences,
- Therefore the answers do not cover the whole country and we suppose it will be necessary to do regional surveys in each country,
- The answers are more subjective than quantitative but probably caused by unclear expression and misunderstanding

## 2. The responses of this survey have concerned an european population of 170 Mio habitants, representing approximately 60.000 HH homozygotes...

## Conclusions (II)

3. It is interesting to note that the HH patients can be treated in several places:

Hospital (day hospital,...)

Blood centre

General practitioner office

Mobile nursing unit

Medical laboratories

Other solutions probably exist, *but all must respect good clinical practices!*



# Conclusions (III)

## 4. A consultation before phlebotomy is carried out in 7 countries

- either by a medical doctor or by a nurse or both and the frequency is variable

## 5. A biological test is organized before phlebotomy in 7 countries

- Hemoglobine is tested each time in 6 out of 7 countries
- Ferritine is tested each time in 1 country and variably in the others countries
- Ferritine + Trf saturation tests are completely variable in 5 countries

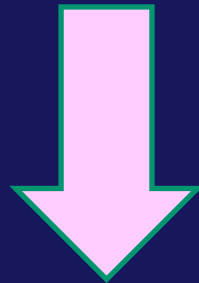
A future EFAPH discussion?

# Which questions are worthwhile investigating?

- Who is doing the consultation?
- Which frequency ?
- Which biological tests?
- Which frequency?

## Conclusions (IV)

6. Few countries set up rules concerning the use of blood from HH patients for transfusion



This subject is of major interest in most countries and 4 countries expressed that this topic must be handled by EFAPH

3 countries are ready to be  
part in a working group!

Portugal  
Hungary  
Norway

Thank you  
everybody!