

## ANNUAL GENERAL MEETING

Rennes, France August 31st , Sept.1st , 2012

Venue : Service des Maladies du Foie - Hôpital Pontchaillou - Rennes, France

**FRIDAY 31 AUGUST**  
**14.00 – 17.30 : ANNUAL GENERAL MEETING**

### **14.00-14.15**      **Registration , Coffee**

14.15- 14-20	Welcome	<b>Dr Barbara Butzeck</b> (EFAPH President), <b>Pr Pierre Brissot</b> (Rennes, France)
14.20- 14.50	What is new about HH ?	<b>Pr Rob Evans</b> (London - UK)
14.50 - 15.10	Hyperferritinaemia, not related to HH Type 1 (dysmetabolic Synd., rare forms HH...)	<b>Pr Pierre Brissot</b> (Rennes - France)
15.10 - 15.30	Listening to the Patients' voice : the first european survey on genetic information !	<b>Pr Graça Porto – Emerência Teixeira</b> (Porto - Portugal)
15.30 - 15.45	EFPAH's expansion ( new associations,...)	<b>Dr B.Butzeck, Ketil Toska</b> (EFAPH VP)

### **15.45 - 16.00**      **Coffee break**

16.00 - 16.20	Follow up on EP lunch debate : GPs awareness raising and "Observatories"	<b>Dr Françoise Courtois</b> (EFAPH Gen.Sec)
16.20 - 16.40	Status and Recommendations of RD Reference Centres in The European Union	<b>Pr Odile Kremp</b> (Orphanet – Inserm US14- France)
16.40 – 17.10	HH-European Reference Network (ERN) – HiroNET Project (Including discussion on the 3 previous items)	<b>Pr Graça Porto</b> (Porto - Portugal)

**19.45**      **Dinner Restaurant Le Galopin**  
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**SATURDAY 1st SEPTEMBER**  
**09.00 – 12.30 : GENERAL ASSEMBLY**

09.00 - 09.20	Activity report 2011 - 2012, approval by voting	<b>Drs F. Courtois, B. Butzeck</b>
09.20 - 09.40	Financial report 2011 - 2012, approval by voting	<b>Jean-Daniel Kahn</b> (EFAPH Treasurer)
09.40 - 10.00	Blood letting/blood transfusion in Europe	<b>Pr Graça Porto</b> (Porto -Portugal)
<b><u>10.00 - 10.15</u></b>	<b><u>Coffee break</u></b>	
10.15 - 11.15	Reports on activities of the national associations in 2011/2012	
11.15 - 11.30	AHO Experience	<b>Alexandre Lecorfec</b> (AHO Vice-President - France)
11.30 - 11.40	Cooperation with EHA	<b>Pr Graça Porto</b> (Porto -Portugal)
11.40 - 11.50	Different questions	
12.00	Conclusion and Perspectives	<b>Dr Barbara Butzeck</b>
<b><u>12.00 – 13.30</u></b>	<b><u>Lunch</u></b> (Meeting room)	