

# 11<sup>th</sup> ANNUAL GENERAL MEETING

Cologne, Germany, Friday Oct.16<sup>th</sup>, 2015

Venue : Altes Refektorium, St.Franziskus-Hospital, Schoensteinstr. 63, Köln-Ehrenfeld

Friday, Oct. 16<sup>th</sup>, 13.00 – 19.00 :

*Haemochromatosis, reflections on clinical and practical aspects in 2015*

## 13.00 – 14.00

## Get together – Buffet , Registration

14.00- 14.15

### WELCOME

**Dr. Barbara Butzeck**, EFAPH  
President

**Pr. Klaus Schlueter-Brust**,  
St.Franziskus-Hospital, Cologne

### *Moderation :*

*Pr CLAUD NIEDERAU*, St.Josef-Hospital Oberhausen

14.15 – 14.35

### **Topic 1: HH GENERAL UPDATE**

**What is new in HH** – Report from BioIron  
Hangzhou China September 2015

**Pr. Pierre Brissot**, INSERM,  
Rennes

14.35- 16.00

### **Topic 2: BLOOD DONATION**

**Blood donation and HH: a European point of view  
from blood establishments** (20 mn)

**Dr. Gilles Follea**, Blood Consult,  
France

**HH and Blood donation: experiences with  
the Cologne model** (15 mn)

**Pr. Birgit Gathof**, University  
Cologne

**Blood donation and HH: the Cataluna approach in  
Spain** (10 mn)

**Dr. Mayka Sanchez**, Head of  
D•IRON, Barcelona

**EFAPH-Survey on blood donation** (10 mn)

**Emerencia Teixeira, Pr. Graça  
Porto**, University Porto

**Round table: towards harmonization in europe  
(30 mn)**

**Pr. Graça Porto**, University Porto

16.00 – 16.15

### **TRANSFERRIN-SATURATION**

**Transferrin-Saturation – Management in HH-  
EFAPH promotes clin. practical recommendations**

**Pr. Pierre Brissot**, INSERM,  
Rennes

16.15 – 16.45

### COFFEE BREAK

16.45 – 18.00

### **Topic 4: HH-ARTHROPATHY**

**HH-Arthropathy – an overview and the  
UK experience** (20 mn)

**Dr. Patrick Kiely**, St.Georges  
Hospital, London,UK

**HH-Arthropathy - Typical features in  
Computertomography** (15 mn)

**Dr. Stephanie Finzel**, University  
Erlangen, Germany

**Anakinra in HH-Arthropathy- study design and  
very preliminary results** (10 mn)

**Pr. Pascal Guggenbuhl**, Rennes,  
France

**Hip and knee replacement in HH-Arthropathy  
(15 mn)**

**Pr. Klaus Schlueter-Brust**,  
St.Franziskus-Hospital, Cologne

**Patients' perspectives and experiences-  
Presentation of a working group** (15 mn)

**Dr. Barbara Butzeck, Pr. Graça  
Porto**, EFAPH

18.00 – 18.45

### **Topic 5: HH - A RARE DISEASE ?**

**Rare forms of HH – European Reference Network  
and General discussion**

**Pr. Domenico Girelli**, University  
Verona, Italy

18.45 -19.00

### *Concluding Remarks*

**Dr. Barbara Butzeck**  
**Pr. Claus Niederau**

20.30

**DINNER** (Venue: old-fashioned restaurant in Cologne)

# 11<sup>th</sup> ANNUAL GENERAL MEETING

Cologne, Saturday Oct.17<sup>th</sup>, 2015

Venue : Stadthotel am Roemerturm, St.Apern Str. 32, Cologne

## *Saturday Oct. 17<sup>th</sup> 09.00 –12.30 : EFAPH GENERAL ASSEMBLY*

09.00 - 09.30	<b>Activity report 2014 - 2015</b> , Projects 2015-2016, approval by voting	<b>Dr. F. Courtois</b> , EFAPH Gen. Secretary / <b>Dr. B.Butzeck</b> Pres
09.30 – 09.45	<b>Financial report 2014</b> , Budget 2015 approval by voting	<b>Dag Erling Stakvik</b> EFAPH Treasurer
09.45 -10.00	<b>Scientific Committee: new members and projects</b>	<b>Pr. Graça Porto</b> , Head of scientific board of EFAPH
10.00- 10.45	<b>A 2014/2015 informal review</b> of the 13 EFAPH member associations	<b>Dr. F. Courtois</b> , EFAPH Gen. Secretary/ <b>Dr. B.Butzeck</b> Pres
10.45 -11.15	<u><b>COFFEE BREAK</b></u>	
11.15 – 12.00	<b>EFAPH statutes: propositions for some modifications</b> <b>Elections of Administrative Board and Executive</b> <b>Committee</b>	<b>Jean-Daniel Kahn</b> , EFAPH Senior Board Advisor
12.00 – 12.15	<b>International Alliance of Haemochromatosis</b> <b>Associations (IAHA)</b> – Update and Strategy for the next 2 years Introduction to the following IAHA meeting	<b>Pr. Robert Evans</b> , IAHA president, UK <b>Ben Marris</b> , IAHA President-elect - Australia
12.30	Conclusions and Perspectives  <i>End of EFAPH Meeting</i>	<b>Dr. Barbara Butzeck</b>
13.00	<u><b>LUNCH</b></u>	
15.30 – 17.30	<b>SIGHTSEEING TOUR COLOGNE</b>	HVD representatives and city guides

**IAHA**

International Alliance of  
**Haemochromatosis**  
Association

## **3<sup>rd</sup> ANNUAL MEETING**

**Cologne, Saturday Oct.18<sup>th</sup>, 2015**

**Venue :** Der Paritätische - Selbsthilfe Kontaktstelle Köln, Marsilstein 2-4 , Cologne

9.00 – 12.00

### **MORNING SESSION**

Introduction of attending international HH-associations

Discussion of relevant haemochromatosis issues.

12.30 – 14.30

### **WORKING LUNCH/AFTERNOON SESSION**

The organization and function of IAHA

Formal AGM, including

- President's report
- Treasurer's report
- Election of office holders
- Looking forward - priorities for the next two years.

15.30

**END OF IAHA MEETING**

**END OF CONFERENCE**