



## 1st ITALIAN THALASSAEMIA MEETING FOR PATIENTS AND HEALTH PROFESSIONALS and 5th EUROPEAN SYMPOSIUM ON RARE ANAEMIAS

**DAY 01 - 15<sup>th</sup> November 2013**

14:00-15:00 **REGISTRATION**

15:00-16:00 **WELCOME SESSION**

**Opening Message from the Italian United**  
M. Bianchi

**Italian Ministry of Health**  
To be confirmed

**President of Provincia of Ferrara**  
M. Zappaterra

**Thalassaemia International Federation (TIF)**  
Haemoglobinopathies on the move: Is Europe ready? Health and migration policy:  
A. Eleftheriou - TIF

**European Network for Rare and Congenital Anaemias (ENERCA)**  
The new e-ENERCA Project: Towards an e-health based European Reference Network (ERN)  
J.L Vives Corrons

**European Commission**  
To be confirmed

16:00-16:30 Coffee Break

16:30-18:30 **PLENARY SESSION I**

**EPIDEMIOLOGY AND PREVENTION OF HAEMOGLOBINOPATHIES:**

**CHAIRPERSON:** B. Gulbis

**Haemoglobinopathies. Current situation of Genetic Diagnosis and Counselling**  
P. Aguilar Martinez

**Prevention of sickle-cell disease. A challenge for increasing patient's quality of life**  
B. Gulbis

**EU Transborder Health Care**  
A. Eleftheriou

**Steps needed to move forward in Italy. A professional point of view**  
To be confirmed

**Steps needed to move forward in Italy .A patient point of view**  
L. Brunetta

18:30-19:00 **HONORARY LECTURE**

**G6PD Deficiency: A never ending history**  
L. Luzzatto

19:00-20:00 **POSTER SESSION**

20:30-22:30 **GALA DINNER**

## **DAY 02 - 16th November 2013**

09:00-10:30

### **PLENARY SESSION II**

#### **THE LABORATORY DIAGNOSIS OF RARE ANAEMIAS**

**CHAIRPERSON : P. Bianchi**

**The diagnosis of haemoglobinopathies: From protein to genome**

M del Mar Mañu

**New technologies for the diagnosis of thalassemia**

C. Harteveld

**Recent progress in the diagnosis of RBC membrane and enzyme disorders**

P. Bianchi

**Hereditary iron metabolism disorders. Where we are?**

C. Camashella

10:30-11:00

**Coffee Break**

11:00-13:00

### **PLENARY SESSION III**

#### **CLINICAL MANAGEMENT OF HAEMOGLOBINOPATHIES**

**CHAIRPERSON: A.Piga**

**The Thalassaemia syndromes**

A.Piga

**The Sickle cell syndromes**

L. Di Franceschi

**Iron Overload: Clinical complications and new diagnostic procedures**

D. Cappellini

**Liver disease and thalassaemia: The Treatment to contrast HCV's complications**

J. Dusheiko

**Osteoporosis and Pain**

A. Giusti

13:00- 14:30 **Lunch**

14:30-16:00

### **INTERACTIVE WORKSHOP WITH PATIENTS**

#### **HAEMOGLOBINOPATHIES AND RARE ANAEMIAS**

G.Constantinou, D.Cappellini, J. Dusheiko, M. Agnostinotis, V.De Sanctis, A.Giusti

**Expert Patient's Program and Patient's rights**( G.Constantinou)

**New Chelators** (D. Cappellini)

**New drugs for HCV treatment in thalassaemic patients** (J. Dusheiko)

**Multi-disciplinary care of haemoglobinopathies** ( M.Angastinotis)

**Endocrinological Problems** ( V. De Sanctis)

**Osteoporosis and Pain** (A. Giusti)

16:30-17:00

Coffee Break

17:00-18:30

**PLENARY SESION IV**

**RECENT KEY ADVANCES IN RARE ANAEMIAS**

CHAIRPERSON: Giuliana Ferrari

**Erythropoietic failure syndromes in paediatrics**

A. Iolascon

**Paroxysmal Nocturnal Haemoglobinuria (PNH)**

A. Hill

**Gene therapy approaches for the cure of thalassemia**

M. Sadelain

**FP7 Projects In Rare Anaemias:**

“Thalamos” - R. Gambari

“EuroFancolen” - J. Bueren

18:30-18:45

**FINAL REMARKS**