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

DAY 01 - 15th 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

Thalassemia 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

EPIEMIOLOGY 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 thalassemic 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**