

The Italian National Blood Centre (CNS), in collaboration with the Italian Association of Hemophilia Centres, the Federation of Haemophilia Associations, the Region of Veneto on behalf of the Health Commission of the State-Regions Conference and the Scuola Superiore Sant'Anna of Pisa, organizes a seminar for the purposes of sharing and disseminating the outcomes of the project, funded by the Italian Ministry of Health within the **CCM projects 2010** (Centro per la prevenzione e il Controllo delle Malattie, Center for Diseases prevention and Control) on the "Definition of a model of taking charge of the patient with congenital bleeding disorders aimed at the prevention and reduction of both health and social impact of the disease and its complications".

The project contributed to define the general framework of the management of patients affected by congenital inherited bleeding disorders in order to identify specific guidelines for both regional planning and institutional accreditation of Haemophilia Centres (HCs).

The event aims at providing an opportunity to enhance knowledge and exchange on HCs accreditation and certification models in use in different European Member States. In addition, the upcoming European Standards for Haemophilia Centres developed in the context of the EUHANET project ([www.euhonet.org](http://www.euhonet.org)), co-funded by the Executive Agency for Health and Consumers and with the CNS as collaborating partner, will be presented.



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*Ministero della Salute*



*Definizione di un modello di presa in carico del paziente portatore di malattie emorragiche congenite finalizzato alla prevenzione e riduzione dell'impatto socio-sanitario della malattia e delle sue complicanze*

**Haemophilia Centres  
certification systems  
across Europe**



**July 11, 2013**

Aula Pocchiari

Istituto Superiore di Sanità

Viale Regina Elena, 299

Rome, Italy



## Morning Session

### Haemophilia Centres certification systems across Europe

08:30 - 09:00 Registration  
09:00 - 09:15 Welcome Address  
President of the Istituto Superiore di sanità, **F. Oleari**  
Italian Ministry of Health, **B. Lorenzin**

#### First session:

### Haemophilia Centres Certification System across Europe

Chairpersons: **G. Grazzini, P. M. Mannucci**  
09:15 - 09:30 The UK experience, **G. Dolan**  
09:30 - 09:45 The Belgian experience, **C. Hermans**  
09:45 - 10:00 The Netherlands experience, **K. Fischer**  
10:00 - 10:15 The Italian Professional Accreditation Model, **P. M. Mannucci**  
10:15 - 10:30 The Italian Institutional Accreditation Model, **G. Calizzani**  
10:30 - 11:00 *Coffee Break*

#### Second session:

### Presentation of the European Haemophilia Standards for Haemophilia Centres

Chairpersons: **G. Calizzani, A. Montserrat Moliner**  
11:00 - 11:15 European Network of Centres of Expertise for Rare Diseases, **A. Montserrat Moliner**  
11:15 - 11:30 EUHANET project, **M. Makris**  
11:30 - 11:45 The methodology for defining the European Standards, **F. Candura**  
11:45 - 12:00 European Standards, **P. Giangrande**  
12:00 - 12:15 The European Haemophilia Consortium perspective, **B. O'Mahony**  
12:15 - 12:30 The European Alliance for Haemophilia and Allied Disorders perspective, **C. Ermanni**  
12:30 - 13:00 Key questions for discussion, **A. Weill, W. Schramm**  
13:00 - 14:00 *Lunch*

## Afternoon Session

### Definizione di un modello di presa in carico del paziente portatore di malattie emorragiche congenite finalizzato alla prevenzione e riduzione dell'impatto socio-sanitario della malattia e delle sue complicanze

14:00 - 14:30 *Saluti Autorità*  
*Ministero della Salute*  
*Commissione Interregionale*  
*Conferenza Stato-Regioni*  
*Centro Nazionale Sangue*

Moderano: **F. Oleari e M. R. Tamburrini**  
14:30 - 14:45 Il piano nazionale malattie rare.  
Il ruolo del Ministero, **S. Arcà**  
14:45 - 15:00 Il piano nazionale malattie rare.  
Il ruolo delle Regioni, **P. Facchin**  
15:00 - 15:15 Panoramica delle Malattie Emorragiche Congenite, **G. Di Minno**  
15:15 - 15:30 Le attuali criticità nell'assistenza, **R. Arcieri**  
15:30 - 15:45 La sostenibilità del modello di cura, **S. Nuti**  
15:45 - 16:00 Le Raccomandazioni sulla programmazione regionale, **G. Calizzani**  
16:00 - 16:15 Le Raccomandazioni sull'accREDITAMENTO istituzionale, **M. La Sai**

16:15 - 17:15 Tavola Rotonda  
Discussants: **D. Taruscio, H.J. Hassan**

Discussione e Conclusioni

## Participants

### Morning Session

Gerard Dolan, *United Kingdom Haemophilia Centre Doctors' Organisation, United Kingdom*  
Kathelijn Fischer, *University Medical Centre Utrecht, Netherlands*  
Paul Giangrande, *Oxford Haemophilia Centre, United Kingdom*  
Cedric Hermans, *Catholic University of Louvain, Belgium*  
Micheal Makris, *University of Sheffield, United Kingdom*  
Antoni Montserrat Moliner, *DG SANCO C2 - Health Information, Luxembourg*  
Brian O'Mahony, *European Haemophilia Consortium, Ireland*  
Wolfgang Schramm, *University of Munich, Germany*  
Alain Weill, *World Federation of Hemophilia, France*  
Gabriele Calizzani, *Italian National Blood Centre*  
Fabio Candura, *European Haemophilia Consortium*  
Giuliano Grazzini, *Italian National Blood Centre*  
Pier Mannuccio Mannucci, *IRCCS Ca' Granda Maggiore Policlinico Hospital Foundation*  
Fabrizio Oleari, *Istituto Superiore di Sanità*

### Afternoon Session

Silvia Arcà, *Italian Ministry of Health*  
Romano Arcieri, *Federation of Haemophilia Associations (FedEmo)*  
Paola Facchin, *Permanent Technical Interregional Coordination Panel on Rare Diseases*  
Hamisa Jane Hassan, *National Registry of Congenital Bleeding Disorders, Istituto Superiore di Sanità*  
Giovanni Di Minno, *Italian Association of Haemophilia Centres (AICE)*  
Sabina Nuti, *Institute of Management, Scuola Superiore Sant'Anna, Pisa*  
Mario Saia, *Veneto Regional Health Authorities*  
Maria Rita Tamburrini, *Italian Ministry of Health*  
Domenica Taruscio, *Italian National Rare Diseases Centre, Istituto Superiore di Sanità*