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.euhanet.org), co-funded by the Executive Agency for Health and Consumers and with the CNS as collaborating partner, will be presented.
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. Hermans
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 ute Sal
Conferenza auto-Rigioni
Centro Nazionale Sangue

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. Nuci

15:45 –16:00  Le Raccomandazioni sulla programmazione regionale, G. Calizzani

16:00 -16:15  Le Raccomandazioni sull’accreditamento stituzionale, M. a 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 (AIUCE)
Sabina Nuti, Institute of Management, Scuola Superiore Sant’Anna, Pisa
Mario Saia, Féneto Regional Health Authorities
Maria Rita Tamburrini, Italian Ministry of Health
Domenica Taruscio, Italian National Rare Diseases Centre, Istituto Superiore di Sanità