



European Haemophilia Consortium Press Release

Cross-border healthcare: The European Haemophilia Consortium calls for mobility of knowledge and a united European safety standards

Brussels, 11 December 2009 - Participants of the 8th European Haemophilia Consortium (EHC) Round Table called for greater mobility of knowledge in the area of rare diseases. The Consortium also called for the adoption of harmonized standards for patient safety and implementation of the comprehensive haemophilia care in every European Member State.

The recent defeat of the proposed Directive on Patients Rights in Cross-border Healthcare dominated the debate and participants could not hide their disappointment over the Council's failure to reach a consensus among the Member States. It was agreed that fears over the economic consequences of the Directive clouded the clear need for the improved rights of patients.

Mr. Enrique Esteller from the Council to the European Union said that the next steps in the Directive are uncertain with the possibility of withdrawal of the proposal by the Commission and the Spanish Presidency continuation of negotiations on this file, which is rather unlikely.

The debate also focused on the need to promote common patient safety standards across Europe for implementation by all Member States in order to safe guard haemophilia patients. Dr. Jean-Marc Spieser, from the Council of Europe (EDQM) communicated the continuous efforts developed by EDQM and its numerous expert committees to ensure united European standards which guarantee that the same product with the same control standards is available wherever the patient is treated, in Europe and beyond.

Dr. Magda Rosenmöller, Associate Professor at IESE Business School, pointed out that mobility of patients is a growing reality and an important opportunity which Member States should treat as an **investment in the future**. Dr Rosenmöller said that Member States must better organise their health systems in order to meet patient needs and allay their financial concerns around cross border care. In her view, the challenges of patient mobility are the lack of: information, quality and continuity of care, as well as mechanisms for compensation of harm.

Mr. Frédéric Destrebecq, CEO of European Union of Medical Specialists (UEMS), stressed the importance of mobility of professionals in cross-border healthcare and the role of mutual recognition of professional qualifications, which is expected to be revised in 2012. He also referred to the Council Recommendation on Rare Diseases adopted in June 2009, which clearly states that "in principle, and where possible, **expertise should travel rather than patients themselves**".

The point of mobility of expertise rather than patients was broadly discussed by the participants reaching a general consensus. Mr. Brian O'Mahony, President of the Irish Haemophilia Society and EHC Steering Committee Member, believes that the key issue for haemophiliacs is the adequate availability of treatment, and the organisation of resources at national level. He said "**the concept of a comprehensive haemophilia care should travel rather than patients** who need to be correctly diagnosed and feel secure in terms of the treatment, entering the hospital in their own country".

Mr. Antoni Montserrat from the European Commission, DG SANCO, highlighted the importance of the Directive on Cross-border Healthcare to ensure the long term framework for the functionality of the European Reference Networks (ERN). He said, "in the light of the recent Council decision now the sustainability and funding of the ERN should be secured". He also highlighted that the most appropriate solution for rare diseases patients is to ensure an adequate access to treatment in all Member States.

Consensus arose on the need for more quality data, cooperation amongst experts and use of new technologies. Echoing the Round Table exchange, the EHC calls for:

- **Enhanced "knowledge" mobility** and use of new technologies to fill information gaps and thus reduce disparities of care across Europe
- **United European standards** to secure **patient safety** in cross-border and home healthcare
- Implementation of a **concept of a comprehensive haemophilia care** in each European country
- **A trustful dialogue between experts** and **data sharing** to increase **cooperation between already existing Centers of Expertise** in the field of Haemophilia

For further information on the outcomes of the event, please go to www.ehc.eu or contact the EHC EU representation office: email: info@ehc.eu; tel. +32 (0)2 213 13 05.