



# European Haemophilia Consortium

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## EHC Position Paper

### The Place of chronic congenital diseases within the EU- Framework for Health Services

Europe is growing together in many aspects of life. It becomes more and more normal that people are working, studying, living or have holidays in an EU-member state which is not their home country. People with special needs/handicaps and/or chronic diseases participate in these developments. Their social integration anywhere in Europe has to be a major issue of the EU politics.

Patients with rare diseases such as Haemophilia can be treated very well today, even if Persons with Haemophilia (PwH) need a lifelong Comprehensive Haemophilia Care and a frequent administration of their clotting factor concentrates (plasma-derived or recombinant).

The European Haemophilia Consortium represents 44 European national member organisations at this time. The quality of treatment varies very much among the member states. Excellent "state of the art- treatment" is available in countries like Austria, France, Germany, UK or Sweden, on the contrary the situation in new member states such as Bulgaria or Romania can be described only as poor.

For patients with severe forms of diseases access to treatment is life saving. However, travelling from one Member State to another to get adequate treatment is neither possible in most cases nor a practical solution on a long-term run.

#### **The European Haemophilia Consortium appeals to the European Commission:**

- Each patient in the EU must have access to state of the art treatment;
- Diagnosis and Treatment of diseases must be free of charge or at least affordable to all EU- citizens;
- Each EU- citizen must have the right to receive adequate treatment in every member state;
- The costs of treatment must be guaranteed by the social/ health care system of the country of residence of the patient;
- Especially in Rare Disorders medical research and special diagnostics or treatment such as surgery, etc., shall be concentrated in some member states.
- Every patient must have access to such Centres of Excellence.

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