



# European Haemophilia Consortium

## EHC Roundtable of Stakeholders

### **Patient mobility: a solution for Haemophilia? 'Who/What should travel? Patients, clinicians, expertise and information on state of the art care?**

**Brussels, 9 December 2009, 09.00am-12.30pm  
Stanhope Hotel Brussels, Rue du Commerce 9, 1000 Brussels**

The 8<sup>th</sup> Round Table of Stakeholders organised by the European Haemophilia Consortium (EHC) will focus on patient mobility, putting particular emphasis on patient with rare diseases and their right to access cross-border healthcare services outside their home country.

Mobility of patients across Europe's borders is a somewhat marginal phenomenon as most patients prefer to be treated as near to home as possible, close to their relatives, in a system they are familiar with, and with providers who speak their language, where they know what they can ask for and what they can expect to receive. Going abroad for treatment is almost never the first option, but is rather the result of specific circumstances for example for patients who live in cross-border regions and have easier access to healthcare in the neighbouring country, patients with diseases for which a specialised treatment is available only in another Member States, patients that choose a specific treatment abroad, etc.

Patients suffering from rare plasma related disorders such as Haemophilia need life-long treatment and frequent administrations of their therapies. Certainly when there is no alternative, the possibility to access care in another Member State should be ensured. For patients suffering from such conditions, access to treatment can be life-saving. However for many patients with severe forms of illnesses, travelling from one country to another for treatment is neither possible nor a practical healthcare solution. There are many challenges facing people with rare diseases, the organisations working on their behalf will therefore remain of critical importance.

The EHC Round Table will discuss the issue of mobility of health professionals and better mobility of data and expertise. The stakeholders will also answer the question on how health professionals travelling over the border can secure best possible treatment for rare disease patients as well as how knowledge and information should travel within Europe.

The rare diseases community already knows the value of national Centres of Excellence. Now the creation of European Reference Networks (ERN) – physical or virtual networking of knowledge and expertise – can provide a high added-value for rare diseases given the limited number of patients and scarcity of expertise at the national level. The stakeholders will discuss their role, structure and practical value to patients and health professionals.

Speakers will also address the issue of the financial burden of patient travelling for treatment, patient safety, the information on the quality and location of healthcare available to rare disease patients, the cultural and language barriers to patient mobility.

The EHC Round Table entitled **"Patient mobility: a solution for Haemophilia? 'Who/What should travel? Patients, clinicians, expertise and information on state of the art care?"** will give clinicians, patient organisations, EU policy makers and the pharmaceutical industry the opportunity to address the different issues surrounding the topic of patient mobility. Special attention will be paid to defining and assessing the criteria required to ensure access to best practice and right to reimbursement which will allow for better management and treatment of the disease.

#### **Introduction to the Topic:**

A decade ago, there was little discussion of the issue of patient mobility at a European level. The Treaty of Amsterdam made clear that health systems are a matter for national governments. It was recognized that freedom of movement of people within Europe required that those people who travelled could obtain health care should an emergency arise and this had been taken care of by Council Regulation (EEC) No. 1408/71.

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Now health systems and health policies across the EU are becoming more interconnected than ever in the past. This is due to many factors, including movement of patients and professionals (facilitated by rulings of the European Court of Justice), common public expectations across Europe, dissemination of new medical technologies and techniques through information technology, and the enlargement of the Union. This increased interconnection raises many health policy issues, including quality and access in cross-border care; information requirements for patients, health professionals and policy-makers; the scope for cooperation on health matters; and how to reconcile national policies with European obligations in general.

To meet these challenges the Commission came forward with a proposal for a Framework Directive 'The application of Patients' Rights in Cross-border Healthcare' on 2<sup>nd</sup> July 2008<sup>1</sup>. The intention of this proposal is not to encourage cross-border healthcare as such, but to ensure that receiving healthcare abroad is beneficial, safe to do so, will be of good quality, and that the procedures for reimbursement are clear, and responsibilities clearly defined and allocated.

The European Parliament's report<sup>2</sup> on this proposal added special rules for patients with rare diseases and disabilities that might need special treatment. According to MEPs, patients affected by rare diseases should have the right to be reimbursed, even if the treatment in question is not provided for by the legislation of their Member State and this shall not be subject to prior authorisation.

The proposal also establishes a framework for European cooperation and creates European Reference Networks (ERN). Rare diseases will be one of the first areas to see the creation of a European Reference Network. The ERN for Rare Diseases will have a strategic role in the improvement of quality treatment for all patients throughout the European Union. The network will include specialised centres catering for a rare disease, or a group of rare diseases.

### **EHC questions to the debate:**

The stakeholders of the EHC Round Table should bring more answers to some of the following questions:

Will the enhanced patient mobility be an opportunity which will bring better access to health care and Centres of Excellence? How will patient mobility affect the various pricing and reimbursement systems that currently exist across Europe? How to make sure that patient travelling abroad for treatment will be reimbursed and protected? How to secure quality and safety standards for haemophilia patients travelling abroad? How should data protection be reconciled with patients' needs, and what systems can best ensure that medical information can be exchanged across frontiers? Will the directive on removing obstacles to cross-border healthcare help to narrow the EU's East-West gap? How to facilitate mobility of expertise and best practice sharing in the field of rare diseases? How can health professionals travelling over the border secure best possible treatment for the rare disease patient? How to improve patients' confidence in cross-border healthcare and ensure that the adequate information on quality of the treatment is provided? Who would deal with patients' complaints with regard to prior authorisation, reimbursement of costs or harm? How can the ERN of highest quality be selected? How will Centres of Excellence be selected as members of the ERN? Who will address new questions and obstacles that arise from such pan-European collaborations such as the question of medical liability in virtual clinics?

### **Set up of the Round Table**

The EHC organises its 8th Round Table discussions as part of a series of Round Table meetings<sup>3</sup> which began in 2007. Some of the items of this Round Table have been discussed in previous debates, the EHC believes that they should be revisited in the light of the Commission's proposal and to see if any progress has been made.

The aim is to share information and knowledge as much as it is to exchange ideas on how to optimally address the issue of patient mobility within the existing framework.

**Participation is upon invitation only.** The EHC is inviting to this Round Table 20-25 representatives with relevant experience including national and relevant European policy-makers, patient organisations, clinicians and industry. During the meeting all invited parties are encouraged to draw attention to their own vision on the topic, thus offering ideas for building the right data framework for enabling optimum access to haemophilia care.

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<sup>1</sup> The EC proposal is available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0414:FIN:EN:PDF>

<sup>2</sup> The EP text is available at: <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P6-TA-2009-0286>

<sup>3</sup> For further reference, please go to our website: <http://www.ehc.eu/index.php?id=57>