

PPTA Position Paper Patient Information

The Plasma Protein Therapeutics Association (PPTA) welcomes the recent discussions aimed at improving patient information throughout the European Union (EU) as initiated at the European High Level Pharmaceutical Forum and following the European Commission's *draft report on current practices with regard to the provision of information to patients on medicinal products* dated 19 April 2007.

Patients suffering from conditions treated with the therapies manufactured by PPTA member companies (e.g. coagulation factors, immunoglobulins) suffer from very specific rare plasma protein deficiency disorders, including haemophilia and other blood clotting disorders, immunodeficiencies and auto-immune diseases. The rarity of some of these disorders often means that information on treatment options, symptoms, diagnostic and access to treatment is not optimal. The relative attention to these conditions and their representing patient groups varies greatly from one member state to another.

However, it is interesting to point out that the WHO has recently published its 15th List of Essential Medicines to be used globally. The WHO list is intended to provide guidance to individual countries in determining which medicines are considered to be essential and in subsequently prioritizing their healthcare resources. Included in that list are both coagulation factors and immunoglobulins. It is therefore unfortunate that information and thereby the access to these therapies are subject to diverging standards in different member states.

PPTA would therefore strongly recommend:

- Promoting public/private partnerships in education/awareness programmes in order to better understand symptoms of the above-mentioned conditions and to improve competency of patients and their advocacy groups
- Improving the understanding of symptoms for rare plasma protein deficiency disorders for the medical community in order to improve diagnosis and therefore the level of treatments
- Launch of EU patient registries on the conditions mentioned above
- Easy to access centralized information on reference centres
- Encouraging use of electronic media and interactive technologies to disseminate and share patient information

PPTA Background Information:

PPTA is the primary advocate for the world's leading producers of plasma-derived and recombinant analogue medicinal products. The medicines produced by PPTA members are used to treat patients suffering from rare life-threatening and/or life-impairing disorders and serious medical conditions including bleeding disorders (e.g. Haemophilia), immune system deficiencies (e.g. Primary Immunodeficiencies), auto-immune diseases, burns and shock.