Plasma Protein Therapeutics Association

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PPTA Position Paper

Draft Directive on the Application of Patients' Rights in Cross-Border Healthcare

The Plasma Protein Therapeutics Association (PPTA)* has followed with great interest the recent developments aimed at improving patient mobility throughout the European Union (EU). The proposals for a Directive on the application of patients' rights in cross-border healthcare published by the European Commission in July 2008 are generally favourable and suggest a number of possible benefits for patients treated with plasma protein therapies. However, the manner in which the political debate is conducted from this point onwards is critical to delivering on these promises and resulting in tangible improvements in care for European citizens.

DG SANCO Commissioner Androulla Vassiliou has used the area of Rare Diseases specifically as an example where there is a significant opportunity for the EU to make a difference to patients through this proposed Directive. PPTA agrees with Commissioner Vassiliou's assertion, but believe that being treated abroad should be a last resort and not used as an opt-out for Member States as to whether they provide specific or specialist treatments for patients suffering from rare diseases.

Patients suffering from rare plasma related disorders such as Primary Immunodeficiencies and Haemophilia for example 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. We know that patients who are treated with plasma protein therapies in the EU have at times experienced difficulties accessing proper treatment in their country of residence and have had to travel to another Member State to receive appropriate treatment. PPTA would therefore encourage the widest access possible to plasma protein therapies and the implementation of appropriate treatment levels of care for rare chronic, congenital life-threatening conditions, especially in Member States where access to treatment is restricted/not optimal in order to ensure better access to care for patients in need across the EU.

Patients with rare plasma related disorders are often mis-diagnosed, the consequence of which is inappropriate treatment and unnecessary associated healthcare costs due to an increased rate of hospitalisations, increased number of missed days of work and increased infection rates. All of these can be avoided if the proper diagnosis is made and appropriate treatment is prescribed. The Directive suggests that reference and information networks and increased use of technological advances to co-ordinate patient healthcare in Europe should be encouraged. PPTA agrees that this would be beneficial to patients. Instead of increasing the mobility of patients, European policies should first target a better mobility of data and expertise. Knowledge and information should travel rather than patients. Therefore, national centres of expertise and European reference networks are important to achieve an enhanced flow of scarce and scattered information and better organisation of patient-centred care.

A good example of how reference networks can help exists in the field of rare plasma protein disorders. European and global level patients groups, such as IPOPI (International Patient Association for Primary Immunodeficiencies) and EHC (European Haemophilia Consortium) have made great efforts to join patients together, and act as reference networks from which both patients and healthcare professionals can benefit from access to information, knowledge and the exchange of ideas. The efforts of patient organisations representing rare plasma disorders was recently recognised by the European Commission, when the patients were invited to take part in a regular consultation process with the Commission's relevant services in order to improve EU action on Rare Diseases.

PPTA would welcome the opportunity to share its experience regarding cross-border healthcare and engage into a constructive dialogue with the decision makers when discussing the Commission proposed directive on the application of patients' rights in cross-border healthcare with the aim to provide appropriate access to treatment for patients.

***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.

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