



The global organisation working to improve the quality of life for people
with primary immunodeficiencies.

IPOPI Position Paper Patient Information

The International Patient Organization for Primary Immunodeficiencies (IPOPI) welcomes the Commission's initiative to issue a draft strategy paper on the provision of information on health issues before the end of 2007 in accordance with 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.

This initiative will ensure that good quality, objective, reliable and non-promotional information on medical products and treatments are made available and should also address the question of the information source's liability.

Information should be validated and standardized across EU member states, and Public Authorities must play a central role.

However, there seems to be a consideration to give more flexibility to the pharmaceutical industry. The general opinion of the patient and consumer organisations, however, is that Direct To Consumer Advertising (DTCA) by the pharmaceutical companies should be prevented as at the moment there is no clear distinction between advertising and information by the pharmaceutical companies.

Patient organisations should be able to solicit information from the pharmaceutical companies in the same way as the regulatory authorities.

It is the opinion of IPOPI that Health Care Professionals should remain the primary source of health information, which would develop private partnership between health professionals and patients.

Patients suffering from primary immunodeficiencies treated with immunoglobulins suffer from very specific rare plasma protein deficiency disorders, 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.

It should be pointed out that the WHO recently has 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 immunoglobulins. It is therefore unfortunate that information and thereby the access to these therapies are subject to diverging standards in different EU member states.

IPOPI would therefore, in accordance with the European Primary Immunodeficiencies Consensus Statement (June 2006), 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*
- Information is a fundamental right for patients and should contribute to empowerment of the patient. However, the availability of information varies greatly between EU member states. The role of the internet is central and increasing, but the information on the internet has to be monitored as there is no proper evaluation of benefits and risks on using the internet-information.*

IPOPI Background Information:

IPOPI is the primary advocate for patients with primary immunodeficiencies in the world working to improve the quality of life for people with primary immunodeficiencies.

Date : 13. June 2007