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To: SANCO-HEALTH-SERVICES-CONSULT
Subject: Patient Mobility: Consultation

Consultation Regarding Community Action on Health Services

IPOPI (International Patient Organisation for Primary Immunodeficiencies) is the only organisation representing the interests of all patients with primary immunodeficiency across Europe. Accordingly we wish to make a brief response to the proposals contained in the above paper issued in Brussels on 26 September 2006.

While we welcome the overall thinking behind this document we would want to indicate in the strongest possible terms that for life long conditions patient mobility is simply not practicable.

IPOPI wishes to highlight the fact that patient mobility for treatment of life-long, life-threatening, illnesses must be and can only be successfully managed in a 'local' context.

In June 2006 IPOPI held a successful Europe-wide conference which was sponsored by the European Commission. While this conference highlighted divergence in diagnosis and management of the primary immunodeficiencies across Europe it was very clear that the answer lies in robust diagnosis and effective management using immunoglobulins for the life-long conditions with which our members are concerned.

It is simply not practical for people with life-long compromised immune systems to travel across Europe seeking diagnosis and treatment.

Our conference demonstrated very well that the encouragement of diagnosis and management, through greater awareness, in each member state would give the very best access to optimum therapy and thereby productive quality of life. Indeed simple education programmes aimed at health care workers could substantially reduce the health budgets in terms of inappropriate therapies and hospitalisations.

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