

From: CSMA [info@csma.org.ua]  
Sent: jeudi 29 novembre 2007 12:18  
To: SANCO RARE DISEASES CONSULTATION  
Cc: Anja Helm  
Subject: Public Consultation

Despite of the fact that Ukraine not a member of EU, the Kharkiv's Foundation «Children with Spinal Muscular Atrophy» is full member of EURORDIS and represents RD - the spinal muscular atrophy in Ukraine.

We wish to vote for the decision the European Commission to make RD a policy priority at EU level. The world is closely connected, therefore, having powerful support Rare Diseases in EU, we are receiving a chance for life of our patients in Ukraine. We are considering possible to give our voices in favor of accepting of this important document.

Not influencing the general style of the document, we feel necessity to reflect in the document the attitude of the European Commission to the closest countries to EU.

a.. Reaction of the European Commission in the form of «letters in support» or the declaration for support for patients communities (non EU members) in attitudes with their national governments (Ukraine);

b.. There is a need for having access to tools of additional diagnostics from the closest countries (Ukraine) - specific tests, expanded diagnostics;

c.. There is a need for acceptance of special documents and the agreements regulating simplified procedure of transfer of bio-samples for diagnostics (or for bio-banks) between the national centers (Ukraine) and EU's centers of expertise;

d.. To distribute decisions concerning Orphan drugs to neighboring countries (a recommendatory level for Health Systems).

Sincerely,

Vitaliy Matyushenko

President of Foundation

"Children with SMA"

Gogolia street, 7

Kharkiv, Ukraine

61057

HomePage - <http://www.csma.org.ua>

MailTo - info@csma.org.ua  
Tel. - +38-050-364-06-73

This paper represents the views of its author on the subject. These views have not been adopted or in any way approved by the Commission and should not be relied upon as a statement of the Commission's or Health & Consumer Protection DG's views. The European Commission does not guarantee the accuracy of the data included in this paper, nor does it accept responsibility for any use made thereof.