

Dear Sirs,

With reference to the "Public Consultation Rare Diseases: Europe's Challenges" **Greek Alliance for Rare Diseases** and **Tuberous Sclerosis Association of Greece** further to agreeing with your comments add a few comments.

Before going to the specific questions I would like to bring to your attention 4 points, which we find important.

First is the problem that R.D patient's face, after those who take care of them and support them cease to exist. In Greece financial support for the care and treatment of patients suffering from a R.D is minimal. Quite a few RD patients are in utmost need of supervision and living quarters. These are patients who are physicaly and/or mentally incapable of living on their own. In Greece we lack these special homes.

Second we believe that there should be a central E.U «coordination office" that would oversee all types of expenditure in the E.U with reference to R.D (research databases data collection orphan drug e.t.c) so that resources are not wasted in doing the same things in different Member State.

Third to make sure that each Member State is registering and collecting data of its RD patients, in order to have the right picture of RD within each Member State and EU.

And last, due to lack of funds or financing projects in some Member States, we believe that these Member States (usually the poorer) should be helped in funding their RD related projects. Help could also come as pressure on governments to establish or increase public spending on RD.

Now to the questions.

Q1) we are happy with current EURORDIS definition.

Q2) yes, for further reference: www.who.int/classification/icd/en/index.htm/

Q3) Yes, especially the E.U reference networks

Q4) Yes, the European Reference Network should privilege the transfer of knowledge and the mobility of patients, by developing electronic services in order to help easy communication access between patients, collecting data for all purposes, sharing data bases and help access between experts on diagnosis and treatment.

The E.U should support financially their activities. There are already many diseases –specific and general database that have been supported by E.U funding e.g. EDDNAL, ITHANET and many others.

Q5) Yes, E.U should support the pooling of efforts and facilitate the coordination across national borders and within Member State. Centralize e-resources.

Q7) Yes we agree, but who will fund these activities, so that less developed Member States can achieve what the more developed ones already have?

Q8) On national scale, for popular specific diseases or more common R.D but Europe wide for rare RD and be easy to access by all Member State.

Q9) Yes.

Q10) Also give special attention on education and training. Special education for patients of RD. Education and training of health care professionals. Education of the general public with ref. to RD.

Q11) yes. Also some form of insurance.

Q12) By defining and supporting socially beneficial prevention and treatment. Industry: support targeted diagnostic protocols and treatment protocols.

Prioritising the needs of patients and families(charities).

Q13) Yes at National Level

Q14) we are of the opinion that EURORDIS cover this subject.

Marianna Lambrou

President of Greek **Alliance for Rare Diseases**
and **Tuberous Sclerosis Association of Greece**

Telephone ++30 210 7660989

Fax ++30 210 7660991

Address: Timotheou Street 99-101,
16232, Athens, Greece

E-mail: gr-pespa@otenet.gr

www.pespa.gr

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.