From: Paul Pyck [paul.pyck@skynet.be]
Sent: dimanche 27 janvier 2008 11:30
To: SANCO RAREDISEASES CONSULTATION
Cc: Susie Cooper; anja.helm@eurordis.org
Subject: Communication on Rare Diseases

Dear Madam, dear Sir,

Let me first present myself. I am the secretary of FEWS. FEWS is the European Federation of all national associations of Williams Syndrome. The letter abbreviation was chosen such to indicate that we represent a rare syndrome (few). As representative of 12 national patient organisation and having contacts with another 10 national WS associations, FEWS finds it very important to communicate on a European level on rare diseases.

The issue of Centres of reference is of primary importance to our WS patients. As WS is a rare syndrome, we almost daily hear stories of people with a late diagnosis and/or unadapted treatment. In some countries or regions, centres of reference with multi-disciplinary teams are already operational and have proven their effectiveness. This must be promoted and supported on European level. This includes

- Setting up such centres with a focus on the Eastern European countries, where this expertise is less available
- The exchange of information between the centres of reference
- Development of lodging facilities, as these centres of reference may be far away of where patients are living

Centres of reference are one of the best ways to improve the support for rare diseases all over Europe.

In general we are very happy with this document, as it is the first such initiative on EU level and due to the rare occurrence, rare diseases need to cooperate even more on a trans-national level than more common diseases.

Unfortunately FEWS did not find anything in the draft text on the empowerment and support of Patient Organisations. Especially the networking on a National and European level of Patient Organisations costs a lot of efforts and money. These contacts are however crucial to improve the support of all persons with a rare syndrome.

Finally I add another reaction of one of our members:

J'ai lu avec intérêt le document "Public consultation rare diseases: europe's challenges". Il s'agit, comme à l'accoutumée pour l'UE, d'un document généraliste qui se veut consensuel, il ne s'y trouve donc pas de grandes révélations ni d'informations très pratiques, directement applicables par nos associations. Ceci étant, il s'agit d'un bon document qui montre bien l'évolution de l'UE depuis 1999 et que, à côté des préoccupations thérapeutiques qui continuent d'occuper une place de choix, on voit apparaître d'autres préoccupations comme l'approche globale du patient dans ses dimensions

prévention, diagnostic, prise en charge... ou encore l'intérêt porté à l'épidémiologie des maladies rares au travers de la définition d'indicateurs de santé qui devraient permettre de mieux dimensionner le problème au niveau européen, la création d'un fonds spécial permettant de disposer de ressources financières, que l'on espère d'un niveau suffisant, sur un long terme et non plus au coup par coup comme ça a été le cas jusqu'à présent... En définitive, je crois qu'il y a lieu d'être plutôt satisfait de l'intérêt que porte l'UE à nos problèmes. Jean Paul/"Autour des Williams".

Best regards,

Paul Pyck

FEWS secretary