To the European Commission
Health & Consumer Protecton Directorate-General
Rare Diseases consultation
HTC 01/198
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February 11th, 2008

Contribution of the German Morbus Wilson patient organisation to the public consultation Rare Diseases (RD): Europe’s Challenges

Dear Sirs,

Thank you very much for being invited to comment on your document, which really is an outstanding project to improve the situation of people living with rare diseases in Europe. We represent the German Patient organisation of Morbus Wilson and are glad to hear that this document will help people with RD all over Europe.
It goes without saying that only when all groups involved with RD work together a success can be the result. Here our specific comments:

The definition of RD should be defined quite clearly – it should be linked to the prevalence. (e.g. rare should be very rare)

Improving RD needs a high investment in Research and Development without national barriers – from the first identification, the diagnosis to the treatments.
Sharing knowledge for those who need to know (without abuse) is one of the big challenges an European inventory could offer. Beside the task to install a RD data base it should be the important aim to keep it alive. This instrument would be as effective as it will be continued and improved on a regular base.

The German Morbus Wilson organisation is considering to develop a national action plan for initiatives, which could be a contribution for all Europeans organisations.

As RD patient association can contribute with their knowledge, they should be included in all processes regarding their specific RD and as they are working on a honourably and voluntary base it should be ensured that there are resources that they can participate in it.

The German Morbus Wilson association is supporting a strategy to access the orphan drugs on an EU scale, e.g. Trientine a specific drug available in UK is not being paid by the insurance companies in Germany. In both countries it is treated for the same RD. It is a life saving drug not licensed in Germany, but with a licence in the U.K.

We think an European Agency on RD will be a great success to give all the small organisations a voice and could really become a visible and recognised institution – hopefully without too much bureaucracy.

Partnerships between industries, charities etc. are very welcome as long as they will support projects for people with RD and will not e.g. only be used for marketing or profit shares.

So finally we are happy and glad to see this project growing and really are looking forward to read a lot of good results for all patients with Rare Diseases.

Yours faithfully,

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for the German Morbus Wilson e.V.

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