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Sent: lundi 14 janvier 2008 15:38  
To: SANCO RARE DISEASES CONSULTATION  
Subject: Comments consultation

Attachments: Consultation RD JJC .doc; European CommissionPharma.doc

To whom it may concern

We would like to congratulate the commission for taking the initiative to draft the document 'European Actions in the field of rare diseases'.

The document was discussed with the participants of the FP6, NoE 'EuroGentest' as well as with the members of the Belgian Steering Committee on 'Rare Diseases and Orphan drugs'. It is the general consensus of all these members that the document contains excellent proposals and that these are indeed greatly needed to improve and harmonize the European approach towards these diseases.

While the document contains a number of very valuable proposals, we would like to stress and explicit some of these, from the point of view of EuroGentest, a DG Research funded Network of Excellence aiming at improving the quality and at harmonizing genetic services in Europe, which is also one of the aims formulated in the document of the commission.

The main comment formulated by EuroGentest is that the quality issues should be clearly formulated and that Europe should build as much as possible and where appropriate on already existing and successful initiatives, such as Orphanet and EuroGentest a.o. which have already created unique tools and structures pertaining to rare diseases, rather than reinventing new structures or activities. The comments and suggestions are introduced in section 4: Objectives (attached).

In addition, a few comments were drafted by a representative of the Flemish Hospital Pharmacists, which pertain more specifically to Orphan drugs. (attached).



Consultation RD JJC  
.doc



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We do hope that we may have contributed to improving the document and do hope that actions along the lines proposed by the commission will be undertaken soon to the benefit of the European citizens.

Sincerely yours,

On behalf of the EuroGentest NoE

The coordinator

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