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European Commission
Health and Consumer Protection Directorate-General
Rare dieases consultation
HTC 01/198
11, Rue Eugène Ruppert
L-2557 Luxembourg

Re. **Public Consultation regarding a European Action in the Field of Rare Diseases**

Dear Sir,

Thank you for the invitation to comment the planned activities of the EU as to rare diseases. As a paediatric surgeon I am concerned with congenital malformations and rare surgical diseases of neonates and infants.

Q1: acceptable, although there is quite a difference of the incidence in the various countries for one and the same disease

Q2: There is a pressing need to improve coding and classification

Q3: Yes; Austria is a small country, therefore the number of treated cases in different places is rather low.

Q4: The transfer of knowledge should be improved by defining of centres of excellence which can be contacted at any time; links to research groups; for the patients contact with other affected patients

Q5:defining of experienced reference laboratories for histological, immunochemical or genetic tests is a must

Q6: no personal experience

Q7:describing best practice is very important, exchange of knowledge and information

Q8: will address mostly metabolic disorders, in my country all medicaments are available

Q9: The mentioned specialised social services such as respite care services, help lines, therapeutic recreation programmes and financial and psychological support are very important
Q10: a really important issue
Q11: Research activities should be coordianted with a centrally surveillance, thus avoiding similar studies at different places; the money for research could be spent for really unique original studies. This affects also the funding policy, funding agencies should be in close cooperation.
Q12:I agree with 4.4 and 4.5
Q13: I feel that action plans are important, it could be on a regional or national level, respectively, depending on the kind of disease.
Q14: All activities could be centrally organised by a European Agency, so I think a feasibility study should be done.

I hope my short comments are sufficient, if not, please feel free to contact me.

With best regards,
Sincerely Yours

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