

Direction de la santé

Dr Androulla Eleftheriou Cyprus Alliance for Rare Disorders (CARD) 31, Ifigenias, 2007 Strovolos, Cyprus

Subject: Treatment on patients with Rare Diseases in small EU Member States

Dear Dr Elefteriou,

With regards to your letter dated 03 February 2017, we would like to thank you for the information provided on the situation of Cyprus in the context of the management of rare diseases.

Luxembourg is now in the process of developing a national plan on rare diseases, aiming to start the implementation in early 2018. Currently we have just appointed a Steering Committee of experts in the field of rare diseases who are discussing the main areas which need to be developed. Their objective is to define a suitable strategy to be adopted in Luxembourg, through a national plan.

Given the size of the country, it is very likely that our strategy will focus on strengthening an already existing EU network of experts, thus facilitating the medical care of our patients in reference centres based in our neighbouring countries. In this context it would be extremely helpful to share information on common challenges, current best practices, and open a dialog between our experts.

Our Steering Committee on Rare Diseases will contact you in the near future to assess the possibility to set-up a meeting in order to continue and develop the discussion in this field.

Should you need any further information, please do not hesitate to contact Francesca Poloni, Coordination Plan National Maladies Rares, Ministère de la Santé, Direction de la Santé, Villa Louvigny, Allée Marconi, L-2120 Luxembourg (<u>francesca.poloni@externe.ms.etat.lu</u>).

Sincerely

Dr Jean-Claude Schmit

Director

Direction de la Santé