Question for written answer E-003486/2015
to the Commission
Rule 130
Jana Žitňanská (ECR)

Subject: Rare diseases - inventory and information sharing

The Commission's Expert Group on Rare Diseases adopted recommendations on the codification of rare diseases at its meeting in November 2014. The joint inventory, guaranteed interoperability, codification and data processing of such diseases are sure to make the lives of EU citizens much easier. The Commission's implementation report on rare diseases (2014) explicitly states that it is important to rapidly improve the codification of these diseases, but fails to put forward any specific, verifiable targets. In this light, I venture the following question:

In the next two years, how does the Commission specifically plan, in so far as its powers and the opportunities open to it allow, to contribute to an effective European-scale inventory of rare diseases?

Which support programmes intended to improve the way the inventory is made, along with codification and the Europe-wide sharing of information on rare diseases, would you say have been successful and why?