Question for written answer E-002253/2016
to the Commission
Rule 130
José Inácio Faria (ALDE) and Carlos Zorrinho (S&D)

Subject: Neonatal screening and severe combined immunodeficiency

Severe combined immunodeficiency (SCID) is the most severe form of primary immunodeficiency, encompassing a group of more than 280 rare diseases. Children born with SCID lack a working immune system and are extremely prone to severe and fatal infections. Newborn SCID screening can give children born with this condition timely access to haematopoietic stem cell transplantation or gene therapy, which, if provided early, are curative treatments. Early intervention can also generate cost savings for healthcare systems.

In the 2014 implementation report on its communication on rare diseases, the Commission undertook to evaluate current population screening (including neonatal screening) strategies for rare diseases.

Does the Commission agree that there is value in further promoting screening practices in Member States, given its competence for supporting cooperation among Member States in the field of health?

Does it also agree that Council recommendations on neonatal screening for rare disorders, as supported by the expert opinion on neonatal screening, are necessary in order to promote such screening as a life-saving tool, as it is for SCID?

Given the poor implementation of SCID screening programmes across the EU, how does the Commission intend to support SCID screening campaigns?