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Committee on the Environment, Public Health and Food Safety

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NOTICE TO MEMBERS

(0001/2013)

Question for Question Time in committee 0001/2013
under Rule 197 of the Rules of Procedure
by Glenis Willmott, Frédérique Ries, Miroslav Mikolášik

Subject: Oral question on "Newborn screening for rare diseases"

The European Parliament has been a driving force for rare disease policy, and newborn screening for rare diseases is something that has not yet been addressed. The EU has a clear competency to act on rare diseases, and on the development of European guidelines for diagnostic tests or population screening. This action is particularly important as neo-natal screening aims not only to significantly improve quality of life but also has cost-saving impact on public health system in Member States.

Severe Combined Immunodeficiency (SCID) is an example of a rare disease which can be effectively screened for at birth. A child born with SCID has no functioning immune system and will die within their first year of life if not diagnosed. However the disease can be screened for at birth, and once diagnosed can be effectively treated or even cured. Screening for SCID is being taken up in some European Member States and elsewhere in the world, and European guidelines on such screening would help all Member States tackle this tragic rare disease. They would also set the framework for other rare diseases for which newborn screening is proven to be effective in the future. Alongside medical and economic aspects, there will of course be ethical considerations.

Early diagnosis and treatment of Severe Combined Immunodeficiency (SCID) can save a baby's life, cure the condition, and is cost-effective compared to the vast amount of treatment the child will require if it is not quickly identified. Will the Commission

therefore recommend that Member States screen newborns for SCID and other rare diseases that can be effectively screened for and then treated or even cured?