Rome, July 20th 2021

TO: Roberto Speranza  
Minister for Health
Pierpaolo Sileri  
Undersecretary of State for Health

Dear Minister, Dear Undersecretary of State for Health

As emerged in the VII “MonitoRare” Report and during its presentation event on July 6th attended by the Undersecretary Sileri, Italy is the leader in Europe in the implementation of Extended Newborn Screening. Newborn Screening is not just a birth test, free and guaranteed for every newborn child, but an authentic journey that span from the early diagnosis to the management of various congenital diseases for which specific treatments exist. If undertaken before the onset of symptoms, they can significantly improve the prognosis of the disease and the quality of life of children, thus avoiding serious disabilities and, sometimes, death.

The Italian panel of pathologies currently screened at birth is the largest in Europe and we are proud of this record. Furthermore, thanks to the work of the Group you set up, the panel will be further implemented in a short time and with increasing regularity.

In short, even in this area we are “European Champions”, although further improvements are always possible. Yet, being first in class is sometimes not a reason for satisfaction. In Europe 30 million people live with rare diseases and the screening journey must become a priority in all countries not exclusively for public health reasons, but also for its great societal and organisational importance.

For this reason, UNIAMO, the Italian Federation of Rare Diseases, on behalf of the Italian community of people with rare diseases, with the endorsement of EURORDIS-Rare Diseases Europe, urge you to promote the Italian Newborn Screening model as a good practice of European relevance, in order to enable all European newborns - and their families – to access this fundamental health right.

We are confident that you will evaluate this initiative as an objective of justice and equity for all children born in Europe, as well as an opportunity for promoting our Country’s model of public health, thus effectively contributing to the achievement of the 2030 Agenda and the Sustainable Development Goals.

UNIAMO Italian Federation of Rare Diseases, with the support of EURORDIS, is ready to provide you with any further information and the support necessary to achieve the goal.

Annalisa M. Scopinaro  
President of UNIAMO F.I.M.R.