Call for Action –
Newborn screening for Severe Combined Immunodeficiency in the European Union

Severe Combined Immunodeficiency (SCID) is an inherited rare health condition in which babies are born with no or a very weak immune system and are unable to fight infections. SCID is a life-threatening paediatric emergency that can be cured through timely access to haematopoietic stem cell transplantation (HSCT). Without timely diagnosis, the treatment is delayed and without effective intervention, SCID leads to death in almost 100% of cases.

Screening for SCID immediately after birth is possible and can be performed on dried blood spot samples which are currently collected in a standardized fashion from all newborns in all European Union Member States. Once SCID is diagnosed, babies can be treated by professionals in specialist centres and provided with HSCT. For the HSCT to be as effective as possible, the transplantation should be done within the first 3 months of life. Delay in recognizing and detecting SCID reduces the success of the available curative option of HSCT and generally leads to fatal consequences. Screening and detection at birth therefore offers the vital chance to intervene before severe infection affects chances of survival and full recovery.

The European Union has identified rare diseases as a health priority since 2008 and encouraged Member States to develop by 2013 national plans or strategies in this field, so as to ensure that patients with rare diseases have access to high-quality care.
The European Commission has been required to prepare a proposal for Council recommendations on newborn screening for some rare disorders. We strongly believe and recommend that SCID should be included within the newborn screening programmes because of the severely life threatening nature of the disease and the fact that there is a life-long cure when SCID is diagnosed in timely fashion.

We, as Members of the European Parliament, call for the following actions to be supported by the European Parliament, European Commission and European Council of the European Union:

- In accordance with the Council Recommendations on an action in the field of rare diseases, as agreed by EU Member States, newborn screening should be prioritised for appropriate conditions in order to improve human health and for the associated economic benefit of managing rare diseases more effectively. Patients who are promptly and effectively diagnosed can begin treatment in order to live a healthier life where they can be net contributors to society rather than net recipients.

- EU Member State should support babies and children suffering from SCID and their families, in order to ensure that patients have access to high-quality care, including diagnosis and treatment capacity, by implementing mandatory screening of newborns for SCID.

- The European Commission and the Council should ensure that the upcoming Council Recommendations on Newborn Screening for some rare disorders includes a list of recommended conditions fulfilling the ten criteria set by the World Health Organisation and referred to in the report from the European Union Network of Experts on Newborn Screening from January 2012.

The undersigning Members of the European Parliament will work towards tabling an Oral Question and a Motion for a Resolution of the European Parliament on Newborn Screening for rare diseases and the inclusion of those that are treatable or even curable as in the case of SCID. Early diagnosis for treatable rare diseases allows for lives to be saved and contributes to a significantly improved health as well as quality of life for patients and their families.