



1st IPOPI PID FORUM SCID Newborn Screening 15 June 2011

Recommendations

1. The European Union must continue its work in supporting its citizens that suffer from rare diseases.
2. Member States should consider Severe Combined Immunodeficiency (SCID) a paediatric emergency and introduce SCID in the obligatory list of diseases newborns are screened for on a routine basis: only early diagnosis (within the first 3.5 months of life) allows access to a timely treatment that greatly improves the survival of a SCID patient.
3. Early diagnosis and treatment reduce significantly the costs and the need of subsequent treatments – while it enables SCID patients to lead a normal life and contribute to society.
4. Early diagnosis of SCID and other PID should be a policy priority for the EU and Member States as it can save lives and allow reducing costs of treatment and care.
5. The EU and Member States should ensure that healthcare professionals receive appropriate information in order to diagnose SCID in a timely fashion and save babies' lives.
6. The European Commission and its advisory bodies such as the EUCERD should ensure that future policy initiatives, including a possible proposal for a Council Recommendation addressing Newborn screening, will call for the inclusion of SCID in the list of diseases newborns are screened for on a routine basis.
7. The EU institutions should collaborate with PID patients' organisations, physicians, and industry to implement the most needed changes in order to save newborn' lives. PID patients' associations and physicians must be consulted by the European- and National institutions on any initiative that concerns them.
8. The European Union must continue to encourage Member States in better diagnosing and treating patients, through financial means and by encouraging sharing of knowledge and best practice, including on newborn screening.