



### **Screen4Rare campaign launched**

#### **Newborn screening for Rare Diseases made stronger by IPOPI, IUIS and ESID**

Screen4Rare is a multi-stakeholder campaign led by IPOPI, the International Society for Neonatal Screening (ISNS) and the European Society for Immunodeficiencies (ESID) aimed at exchanging knowledge and best practices on Newborn Screening (NBS) for Rare Diseases. It hopes to ensure that all babies born in the EU can have equal access to Newborn Screening (NBS) which is life-saving for babies with conditions such as Severe Combined Immunodeficiencies (SCID). The initiative [has gone live](#) in June as a Stakeholders Network on the EU Health Policy Platform, an interactive platform developed by the European Commission that allows sharing of knowledge and information, in the case of Share4Rare for Newborn Screening for Rare Diseases.

Screen4Rare builds on a series of IPOPI's NBS Rare Diseases actions such as a recent [Call to Action](#) that gathered the support of 30 Members of the European Parliament and a successful event in December 2019 at the European Parliament in Brussels (Belgium).



### **PLUS Open Letter on COVID-19 to EU Member States**

The need for continued access to plasma-derived medicinal products and strengthening of blood and plasma collection.

The current COVID-19 outbreak brought about a drop in blood and plasma donation frequency due to confinement and social distancing measures. For IPOPI, as well as for PLUS (Platform of Plasma Proteins Users) of which IPOPI is a member, health safety of patients whose lives depend solely on plasma derived products, such as, primary immunodeficiency patients on replacement immunoglobulin, is tied with two main aspects: more balanced plasma collection between the different world regions and in the free circulation of plasma-derived medicinal products across

world countries. PLUS has published an Open Letter address to the European EU Member States that you can read [here](#). The Letter also stresses that there is a need to develop a contingency plan for the different plasma-derived medicinal products so that in event of shortages, allocation would be managed according to prioritisation, thus ensuring that patient populations can continue to access according to their needs.

About PLUS: PLUS is a coalition of organisations which represent the views of over 110,000 patients in Europe who are regular users of plasma or plasma derived products. We represent the views of the European Haemophilia Consortium (EHC), the World Federation of Hemophilia (WFH), the International Patients Organisation for Primary Immune Deficiencies (IPOPI), Alpha-1 Plus, the GBS/CIDP Foundation, Hereditary Angio-Oedema International (HAEI) and the ITP Support Association.