Primary immunodeficiency diseases (PIDs) are a group of more than 350 rare, chronic disorders in which part of the body’s immune system is missing or functions improperly. While not contagious, these diseases are caused by hereditary or genetic defects. Although some disorders are present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender.

![Diagram showing the number of registered patients in the EU (June 2014)](image)

Severe Combined Immune Deficiency (SCID) is the most severe form of primary immunodeficiency (PID) condition. Affected children have very little or no immune system. They are therefore highly susceptible to bacterial, viral, fungal and opportunistic infections. The treatment and prevention of such infections may prolong life but this does not cure SCID.

SCID is also the only form of PIDs that can be cured with treatments. Rapid access to therapy within the first 3.5 months of life has been shown.

![Pie chart showing children younger than age 15 years](image)

>90% survival rate

There is strong evidence that in families with multiple cases of SCID the outlook for the firstborn child is significantly worse than that for any subsequent children. This is because the early diagnosis of SCID in second/consequent children allows definite treatment before the onset of a potential severe infection.

![Icon showing a family](image)

OUTLOOK FOR SIBLINGS

NEW-BORN SCREENING FOR SCID is crucial to ensure babies can be diagnosed as early as possible and access life-saving treatment rapidly. The chances of curing babies with SCID decrease with time.

![Icon showing a baby with a stethoscope](image)

$50,000-100,000 cost reduction per case

EARLY DETECTION OF SCID could reduce the cost of treatment by $50,000-100,000 per case. According to a recent Swedish study, the total savings per child was over $120,000 comparing the mean cost per child of $301,832 for babies who accessed their treatment early and $423,642 for those accessing treatment late (after 6 months of age).

SCID NEW-BORN SCREENING is established in the USA, Israel, New Zealand, and Norway and several EU Member States are currently running national pilot programmes.