Storage and use of the blood sample
After screening has been performed, the remaining blood sample will be stored as a de-identified sample in the National Unit for Newborn Screening’s diagnostic biobank. Storage of the sample allows for the test to be repeated if there is any doubt about a diagnosis, and potentially for supplementary tests not available when the baby was born. The sample may also be used in our laboratory for further development of newborn screening techniques. The blood sample will be destroyed after six years.

Illustration photo: Jo Michael

SCREENING FOR SEVERE COMBINED IMMUNODEFICIENCY (SCID)

We screen because we can treat and cure!
Norwegian National Unit for Newborn Screening, Oslo University Hospital

Oslo University Hospital
Women and Children’s Division
Norwegian National Unit for Newborn Screening

Rikshospitalet
Sognsvannsveien 20
Postboks 4950, Nydalen
0424 Oslo
Tlf: 02770
Email: nyfodtscreeningen@ous-hf.no
Web: http://www.oslo-universitetssykehus.no/nyfodtscreeningen

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We screen because we can treat and cure!
Norwegian National Unit for Newborn Screening, Oslo University Hospital
**SCID-SCREENING**

Severe combined immunodeficiency (SCID) is a life threatening condition, which is fatal if untreated.

In the existing newborn screening programme all newborns are offered screening for 23 rare, congenital disorders for which early treatment is vital. We are now performing a study for an additional disorder, severe combined immunodeficiency, which we plan to include in the newborn screening programme.

**SCID**

Severe combined immunodeficiency (SCID) is a rare disorder, which occurs in children who lack an important part of the immune system (the T-cells). If the disorder is not diagnosed and treated, the child will die during the first year of life. If SCID is treated by age three months, the survival rate after a hematopoetic stem cell transplantation increases dramatically. Without screening, children are often diagnosed late, usually after developing a life-threatening infection.

![Illustration photo: Jo Michael]

**The test**

The test for SCID uses the same blood sample that is used for screening for the other disorders in the newborn screening programme. The blood sample is taken from the baby's heel between 48 and 72 hours after birth and is sent to the Norwegian National Unit for Newborn Screening Laboratory at Oslo University Hospital. No extra blood test is needed. The study protocol requires that the parents have received information about the test and given their consent. Parents must sign the consent form in order for their child to be tested.

![The sample for SCID-testing is taken from the blood sample card that is used for regular newborn screening.]

**What happens after the test**

When the test result is normal, the parents will not be contacted. If there is suspicion of the possibility of SCID, the parents will be contacted immediately by a doctor to arrange for further testing. In these cases we will also analyze a set of genes known to be associated with serious immunodeficiency disorders. In rare cases when technically quality of the newborn screening blood test is poor, the parents will be contacted by the hospital/clinic where the baby was born to ask for a new blood sample. This does not mean that there is any suspicion of disease.

**How reliable is the screening?**

Rarely, especially in premature babies, the test results may suggest that a baby has SCID even though the baby does not. Follow-up testing will quickly resolve the situation and remove any uncertainty about whether the baby has SCID or not.

**Participation in SCID screening**

The procedure requires that the parents have received information about screening for SCID. Parents who want their baby to be tested must sign the consent form which is returned to the Norwegian National Unit for Newborn Screening at Oslo University Hospital.