



UK NSC Galactosaemia recommendation

Following a review of the evidence against strict criteria, the UK NSC does not currently recommend universal screening for Galactosaemia in newborn babies.

Galactosaemia is an inherited condition which causes excessive amounts of galactose, a type of sugar, to accumulate in the blood and other tissues. An excessive amount can be toxic and can cause long term problems such as cataracts, learning difficulties, growth restriction, speech and behaviour problems and, in women, premature menopause.

Galactosaemia can also cause illness such as vomiting and diarrhoea, liver failure and infection. In rare cases it can be fatal for newborn babies.

Key findings supporting the UK NSC recommendation

- Screening and treatment do not prevent the long term problems caused by Galactosaemia.
- Screening tests will identify babies with different forms of the condition who may never experience any symptoms or who may only develop milder symptoms.
- A special diet has been shown to reduce the severity of symptoms in the baby's first month. However the contribution of screening would be limited as some babies who are severely affected would develop symptoms before the screening test result was available. Others with the disease are already identified through tests within the current newborn screening programme.

The UK NSC regularly reviews its recommendations on screening for different conditions in the light of new research evidence becoming available.

To find out more about the UK NSC's Galactosaemia recommendation, please visit:

www.screening.nhs.uk/galactosaemia

The UK National Screening Committee (UK NSC) is chaired by the Deputy Chief Medical Officer for England, advises Ministers and the NHS in the four UK countries about all aspects of screening and supports implementation of screening programmes. Using research evidence, pilot programmes and economic evaluation, it assesses the evidence for programmes against a set of internationally recognised criteria covering the condition, the test, the treatment options and the effectiveness and acceptability of the screening programme. Assessing programmes in this way is intended to ensure that they do more good than harm at a reasonable cost. The UK NSC also sets up practical mechanisms to oversee the introduction of new programmes in the English NHS and monitors effectiveness and quality of these programmes.

Find out more about the UK National Screening Committee at www.screening.nhs.uk. The UK NSC evidence review process is described at www.screening.nhs.uk/policyreview and a list of all UK NSC recommendations can be found at www.screening.nhs.uk/recommendations

The UK NSC is supported by Public Health England (www.gov.uk/phe).