



Professor Bob Steele

Chair, National Screening Committee

**15<sup>th</sup> June 2017**

**Screening for Severe Combined ImmunoDeficiency (SCID) in neonates**

Dear Professor Steele,

UK-PIN strongly supports the introduction of neonatal screening for severe combined immunodeficiency (SCID) in the UK. Early diagnosis significantly improves the outcome of haematopoietic stem cell transplantation (HSCT) and gene therapy, curative procedures. Delayed diagnosis increases the risk of death from infection prior to treatment.

Current UK practice is still entirely dependent on GPs and paediatricians identifying early signs that might suggest a diagnosis of SCID. This means that the perfect time for HSCT in the early newborn period (<3 months of age) is often missed.

SCID screening programmes are now well established in 41 states in the USA and many European countries now have pilot projects. Growing evidence confirms that the screening test involving quantifying TRECs on Guthrie blood cards has good sensitivity and specificity. In terms of cost effectiveness, it is becoming clear that the costs of delayed diagnosis of SCID in terms of additional healthcare resources (extended paediatric intensive care laminar flow isolation) to manage infections and more complex HSCT are very substantial and likely to greatly outweighs the cost of screening. Accordingly, UK-PIN believes that now is the time to introduce universal screening for SCID in the UK.

On behalf of the Steering Committee of UK-PIN

A handwritten signature in black ink that reads 'Gavin Spickett'.

Dr Gavin Spickett

Consultant Immunologist

Newcastle upon Tyne

A handwritten signature in black ink that reads 'Peter Arkwright'.

Dr Peter Arkwright

Consultant Paediatric Immunologist

Manchester

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