Call for Action - SCID New Born Screening

We believe that Severe Combined Immunodeficiency (SCID), sometimes known as ‘bubble boy disease’ should be prioritised by the Government and the UK National Screening Committee as a matter of urgency and that it be placed on the new born screening list.

SCID is a rare genetic disorder involving a defective antibody response, caused by a genetic mutation. SCID is a Primary Immunodeficiency (PID), part of a large group of over 280 different disorders caused when some components of the immune system do not work properly.

The International Patient Organisation for Primary Immunodeficiencies (IPOPI) and the patient group, Primary Immunodeficiencies UK (PID UK), are campaigning for improved treatment and outcomes for SCID, aiming to screen every new born baby in the UK so that if the baby is found to have the disease following screening it can be protected by antibiotics and immunoglobulin. Doctors would then be able to perform an early transplant or gene therapy would be able to be performed. This is also a cost-effective solution which could save the NHS money over the longer term.

In order for SCID to be listed by the UK National Screening Committee, we want to ensure that there is as wide a support base as possible for its inclusion. The Committee is due to meet on the 23rd June to decide whether SCID should be added to the new born screening list and as part of the overall campaign we would like to see the following action undertaken by the Government:

- Recognise SCID as a disease that should be listed for new born screening by the UK National Screening Committee as soon as possible.
- Recognise that the UK is at risk of falling behind other countries if it does not adopt new born screening for SCID.
- That the 23rd June meeting of the UK National Screening Committee is an opportunity for the Government to honour its commitment to ensure that all UK citizens receive the best possible healthcare and treatment, whatever the disease.

Signatories to the Call for Action are below:

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Chairperson
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Dr Susan Walsh
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