PID UK
Supporting families affected by primary immunodeficiencies

Primary Immunodeficiency UK
PO Box 6970
Basingstoke
RG24 4XL
0800 987 8986
hello@piduk.org
www.piduk.org

Rt Hon Matt Hancock MP
Secretary of State for Health and Social Care
House of Commons
London
SW1A 0AA

Dr Susan Walsh
Director, PID UK

21 November 2018

Dear Secretary of State for Health and Social Care,

Funding for the evaluation of a UK Newborn Screening Programme for SCID

I am writing as Director of Primary Immunodeficiency UK (PID UK; www.piduk.org), a patient support organisation representing people who are affected by genetic disorders that affect the immune system.

PID UK has been campaigning for the last six years to implement a newborn screening programme for severe combined immunodeficiency (SCID), a condition that leads to severe abnormalities of the immune system's development and function.

Infants with SCID typically experience problems with serious and potentially life-threatening infections in the first few months of life. SCID is fatal within the first year of life without correction of the underlying immune deficiency. Haematopoietic stem cell transplant (HSCT) and gene therapy offer curative treatment options for SCID and evidence shows these have a 95% success rate. Early identification of SCID through newborn screening would allow prompt intervention using antibiotics and immunoglobulin before infections occur, giving children the best chance of successful curative therapy.

Screening will use the latest technology to detect T-cell receptor excision circles in DNA isolated from Guthrie blood spots. The cost of screening is outweighed by the costs of delayed diagnosis in terms of healthcare resources (extended paediatric intensive care laminar flow isolation) to manage infections and more complicated HSCT procedures are substantial. The human cost of losing a baby to SCID, when SCID can be cured if detected early enough, is incalculable. The UK is falling behind other countries in SCID screening. In the USA 98% of all newborns are screened for SCID and many EU member states have national programmes or regional pilot studies.

SUPPORTED BY

PID UK is part of Genetic Disorders UK (registered charity number 1141583 and registered company number 7564771). The registered address is Orchard House, 2 Atwood, Little Bookham, Surrey, KT23 3BH.

In 2017 the UK National Screening Committee recommended that newborn screening for SCID be evaluated before deciding to move to full implementation. Over the last year PID UK has been working with the SCID Evaluation Oversight Group and subcommittees to identify the most appropriate screening tools, developing clinical pathways, information for families and training programmes for healthcare professionals. However, we await a decision from the Department of Health on funding (circa £5m) to progress these plans.

I urge you, on behalf of the PID community, to commit the necessary funding to allow the pilot evaluation study to proceed. The process for clinical and technical validation has been agreed, testing sites and protocols are in place, but there remains a lead time following confirmation of funding to employ the staff and order the reagents for testing, so delays now continue to prolong the implementation date.

Please confirm funding. This project will save children's lives and ensure that the UK is not left behind in implementing a newborn screening programme for this fatal condition. I look forward to hearing from you.

Yours sincerely,

Dr Susan Walsh
Director of PID UK
Email: susan.walsh@piduk.org