

## Office of the National Director Public Health

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## Oifig an Stiúrthóir Náisiúnta Sláinte Poiblí

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## BY EMAIL ONLY

Deputy Colm Burke Dáil Éireann Leinster House Kildare Street Dublin 2

29<sup>th</sup> May 2023

PQ 22584/23- Deputy Colm Burke- To ask the Minister for Health the steps taken to date in relation to furthering the expansion of the heel prick test for newborn screening in Ireland, with regard to specific testing for Severe Immunodeficiency (SCID); and if he will make a statement on the matter.

PQ 22585/23-Deputy Colm Burke-To ask the Minister for Health the further investment, if any, that will be required in terms of staffing and equipment requirements for the purposes of including Severe immunodeficiency (SCID) in the heel prick test for newborn screening in Ireland; and if he will make a statement on the matter.

PQ 22586/23- Deputy Colm Burke-To ask the Minister for Health the anticipated timeline envisaged for including Severe Immunodeficiency (SCID) in the heel prick test for newborn screening in Ireland; when parents in Ireland can expect SCID to be added to such test; and if he will make a statement on the matter.

Dear Deputy Burke,

Thank you for your representation.

Minister Donnelly approved the NSAC recommendation to add screening for all-type SCIDs to the National Newborn Bloodspot Screening Programme (NNBSP) earlier this year, and has requested that the HSE progress the service planning processes required for its implementation.

The addition of any new condition to the NNBSP requires a substantial amount of programme planning and technical laboratory validation and verification before screening can commence.

A large number of considerations are required including, but not limited to: - the operational and clinical complexities around the screening method for SCID (TRECs) - this is not currently a methodology employed within the NNBSP - the programme expansion capacity (additional medical scientists and other support staff) and the physical ability to facilitate this expansion in the context of significant space compromise at the current site at CHI Temple Street - the complex preparations required for the move of the Newborn Screening Laboratory to the new National Children's Hospital site at St James, with maintained service delivery.



This process is due to commence during 2024 Therefore it is not expected that screening for SCID will commence until after the relocation to the new National Children's Hospital has been completed, and providing that the service planning requirements and resources for expansion of the NNBSP are met.

Yours sincerely

Niamh Kelly

Niamh Kelly General Manager National Public Health

