



## Rachel Stephen-Smith MLA

Minister for Aboriginal and Torres Strait Islander Affairs  
Minister for Children, Youth and Families  
Minister for Health  
Member for Kurrajong

Mr Tom Duncan  
Clerk  
ACT Legislative Assembly  
GPO Box 1020  
CANBERRA ACT 2601

Dear Mr ~~Duncan~~ Tom

Thank you for your letter of 11 February 2020 regarding petitions No 21-19 and 1-20 in relation to newborn bloodspot screening for Severe Combined Immune Deficiency (SCID), tabled in the Legislative Assembly by Ms Caroline Le Couteur MLA on 11 February 2020. In accordance with Standing Order 100, my response to these petitions follows.

I am advised that the Immune Deficiencies Foundation of Australia (IDFA) is advocating strongly for SCID to be included in the Australian Newborn Bloodspot Screening program to support earliest diagnosis and treatment and has started online e-petitions to Australian State and Territory governments including the ACT.

Decisions about tests for inclusion or removal in national newborn bloodspot screening are overseen by COAG Health Council on advice from the Standing Committee on Screening. ACT newborns are currently screened for 25 medical disorders. The condition SCID is not currently part of the ongoing newborn bloodspot screening program. However, I am pleased to advise that NSW is conducting a pilot SCID study and, as part of that study, ACT newborns are receiving this additional screening.

I am advised that the Standing Committee on Screening is currently reviewing SCID for inclusion in the Australia Newborn Bloodspot Screening program. A recommended ACT position on ongoing screening for SCID will be provided to me for consideration once the advice of the Standing Committee on Screening recommendation is known and the results of the NSW SCID pilot study are available.

Yours sincerely

Rachel Stephen-Smith MLA  
12 MAY 2020

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### ACT Legislative Assembly

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