Cabinet Secretary for Health and Social Care
Rùnaire a' Chaibineit airson Slàinte agus Cùram Sòisealta
Neil Gray MSP
Niall Gray BPA
T: 0300 244 4000
E: scottish.ministers@gov.scot

Scottish Government
Riaghaltas na h-Alba

Clare Haughey MSP
Convener
Health, Social Care and Sport Committee
Scottish Parliament
Edinburgh
EH99 1SP

HSCS.committee@Parliament.Scot

20 March 2026

Dear Clare

SPINAL MUSCULAR ATROPHY NEWBORN SCREENING

I am writing to advise the Committee that on 23 March 2026, Scotland will become the first UK nation to begin a newborn screening In Service Evaluation (ISE) for the condition Spinal Muscular Atrophy (SMA).

SMA is a rare, progressive genetic condition that can cause severe symptoms including muscle weakness, problems with breathing or swallowing, and restricted movement. Prior to the introduction of treatment options, those born with SMA type 1, the most common and most severe type, had a typical life expectancy of two years old. However, Scotland is the first country in the UK to have all three licensed disease-modifying treatments for SMA routinely available on the NHS. As a result of these treatments, those born with SMA can now live longer and achieve more developmental milestones.

The evidence to date also indicates that earlier treatment – ideally before symptoms develop – may improve outcomes. This is why Scotland has agreed to participate in the ISE, so that children can begin experiencing any potential benefits as soon as possible.

The ISE in Scotland is currently intended to run for two years. The screening will be conducted using the blood sample taken during the existing newborn bloodspot test, and has been made possible by funding generously provided by Novartis, with a contribution from the Scottish Government.

The Scottish Government will continue to be guided by the UK National Screening Committee (UK NSC), an expert group which advises all four UK nations on screening policy. The UK NSC requires further supporting evidence before it can recommend SMA screening as a long term addition to the newborn screening programme. The evidence generated by the Scottish ISE will be submitted to the National Institute for Health and Care Research (NIHR), which will analyse it alongside data from the planned SMA ISE in England. It is expected that the evidence will allow the UK NSC to make a recommendation

on whether SMA screening should be introduced as a formal screening programme in the UK.

The NHS and Public Health Scotland have updated information for healthcare professionals and parents of babies born from 23 March to reflect the ISE. The Director of Screening, families affected by SMA and representatives for Spinal Muscular Atrophy UK and Novartis visited the Queen Elizabeth University Hospital on 18 March, where the screening laboratory is based, to learn more about the process of SMA screening. The media were invited to this visit, and have been asked to release their coverage on the day of the launch to help raise public awareness of the ISE.

I am extremely grateful for the extensive work that has been undertaken to make this ISE possible. Firstly, NHS Greater Glasgow and Clyde and the newborn screening laboratory have undertaken considerable work to prepare for implementation, including procuring the necessary equipment and providing laboratory training. I must also thank those who have raised awareness of SMA screening and its benefits, including the charity SMA UK (and in particular CEO Giles Lomax) and the families affected by SMA who have campaigned for the potential benefits of SMA screening. Special thanks are also due to Dr Catherine McWilliam, Lead Clinician for the Scottish Muscle Network; Prof. Zosia Miedzybrodzka, who recently was recognised with an OBE for services to Medical Genetics and Research; and Bob Doris MSP who, along with these key stakeholders, first brought this opportunity to my attention.

Finally, I again acknowledge and express my gratitude for the generosity of Novartis, whose significant funding has been instrumental.

Yours sincerely

NEIL GRAY