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Clare Haughey MSP
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Health, Social Care and Sport Committee
Scottish Parliament
Edinburgh
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Dear Clare

Spinal Muscular Atrophy Screening In Service Evaluation

I am writing to you to advise that I am announcing to Parliament that Scotland will participate in an in-service evaluation (ISE) of screening for Spinal Muscular Atrophy (SMA) in newborn babies.

SMA is a genetic neuromuscular disease that causes muscles to weaken and waste away. Around three or four children in Scotland are diagnosed with SMA annually. Type 1 SMA is the most common form, and is typically diagnosed at around 6 months old.

In recent years, treatments have become available for this condition; however, there is some evidence to suggest that these are most effective when administered before symptoms appear, which is generally at around 3 months old in those with Type 1 SMA. As a result, there are growing calls for SMA to be introduced into Scotland's new born screening programme.

Scotland's screening policy relies on recommendations made by the UK National Screening Committee (UK NSC), an independent scientific body that provides advice on screening policy to all four UK nations. To date, the UK NSC has not recommended SMA screening, on the grounds that more evidence is needed before a definitive decision can be made, particularly around the impact of screening on those diagnosed with SMA. The Committee has stated that an ISE will generate the necessary evidence.

The pharmaceutical company Novartis and the Scottish Government have now agreed to provide funding for Scotland to participate in the ISE for an initial two years. As you know, industry funding for these kinds of research projects is common practice, and my officials are assured that NHS GGC and Novartis have made the necessary arrangements to guarantee the independence of the project.

I am very proud to say that, as a result of this initiative, Scotland will become the first country in the UK to offer national SMA screening. The evaluation will allow us to contribute to an important evidence base, while potentially improving outcomes for babies who may be identified and offered earlier treatment. England is also preparing for an ISE, which is expected to commence in designated areas in 2027.

I am hopeful that these joint efforts will allow the UK NSC to make a final decision on SMA screening, and I am enormously grateful to those organisations and campaigners – in particular SMA UK, and Bob Doris MSP – who have worked so hard to raise awareness of screening's potential benefits.

Yours sincerely

Neil Gray

NEIL GRAY

Annex A – Government Initiated Question

Can the Scottish Government provide an update on its plans to pilot Spinal Muscular Atrophy screening in Scotland?

Based on current planning, in early 2026, Scotland will become the first country in the UK to begin an in service evaluation (ISE) of Spinal Muscular Atrophy (SMA) screening. Under the plans, all babies in Scotland will be offered screening for the condition for at least the next two years.

The Scottish Government recognises that SMA can be devastating for babies and families, and supports any intervention that can be shown to improve the quality of life for those affected.

While there is evidence around the benefits of SMA screening, the UK National Screening Committee (UK NSC) requires further supporting evidence before it can recommend it as a long term part of the newborn screening programme.

This ISE will allow the NHS to potentially find and treat babies with SMA earlier than they otherwise might have, and will generate valuable data to inform the UK NSC's final recommendation on SMA screening.

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.