Houses of Parliament
London
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Dear Rt Hon Wes Streeting MP,

I write on behalf of the Access to Medicines and Medical Devices All-Party Parliamentary Group to raise concerns surrounding the delay in the UK National Screening Committee's (UK NSC) review of the case for introducing Newborn Screening for Spinal Muscular Atrophy (SMA). Originally started in 2022, it remains unclear when this review will conclude.

In July 2024, the UK NSC outlined that newborn screening for SMA could potentially start from mid-to-late 2025 as part of an 'in-service evaluation' (ISE).

To inform this, the National Institute for Health and Care Research (NIHR) issued a brief to researchers to outline what questions the ISE needs to answer and how, which was due to be published in 'late summer 2024'.

After significant delay, this was published in May 2025, however, a final decision on the research team to coordinate the ISE, and the funding to be allocated, are not expected until April 2026.

Following recent stakeholder discussions, it has been estimated that it could be as long as four years between screening the first baby as part of an ISE in England and the UK NSC issuing a formal recommendation on whether SMA screening should be included in routine practice in the NHS.

2031 is simply not good enough. As I am sure you are aware, SMA is a life-threatening genetic disorder where time is of the essence.

Left untreated, around 90% of babies born with the condition will either die before their second birthday or require permanent ventilation to keep them alive.

Currently, in the UK, a diagnosis can only take place once symptoms appear, usually within the first six months of life, but by this point the damage caused by the condition is irreversible.

As a result, even once treatment is initiated, most babies diagnosed with SMA will never walk independently, and many will need mechanical ventilation, nutritional support and 24/7 care.

Newborn screening can prevent these tragic outcomes and is also the financially sound option, current estimates show it could deliver an annual saving of £62.2 million. Furthermore, its introduction also fits with the goals of the government.

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Moving from sickness to a prevention focussed health service. Second, delivering on the ambitions of the UK Rare Disease Action Plan including a commitment to improve decision making around which conditions to screen for at birth. And last, to improve our comparative healthcare position among international partners.

The UK's Newborn Screening programme currently ranks 23rd out of 30 European Countries. In just 3 years it fell five places from its position at 18th in 2022.

Newborn Screening for Muscular Atrophy would not only get the UK on a fair footing, but more importantly significantly benefit the lives of babies across the UK who are developing life-long illness that has the potential to be largely mitigated.

Therefore, we have a series of asks that we would value your support on:

- To urge your department and the UK NSC to publish clear timelines for the implementation of the ISE for SMA. Additionally, further clarification should be given from the NIHR on its recent 'call to researchers', specifically how it intends to address outstanding evidence gaps related to the ISE for SMA and support timely decision making on newborn screening.
- To ensure the UK NSC's evaluation of newborn screening for SMA incorporates data across all regions of the country
- To ask the government and the UK NSC to publish an assessment of the impact that delays in access to newborn screening for SMA will have on the populations not covered within the scope of the upcoming SMA ISE

SMA continues to debilitate families; without urgent action, or clarity on current reviews we are leaving them at the will of this life-threatening genetic disorder.

Best wishes,

Freddie van Mierlo MP
**Chair of the Access to Medicines and Medical Devices APPG**