**Insert your address here**

To **insert MP name here**

**Urgent need to expedite the decision to screen all babies in the UK for Spinal Muscular Atrophy**

**I /(My** ***(insert relationship i.e. .. son/daughter/grandchild/…)*** live**/s** with SMA type #.

There is approximately one baby born every four days in UK with Spinal Muscular Atrophy (SMA). A rare, neuromuscular condition which causes progressive muscle wasting and weakness, it affects all areas of the body including crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. How severely people are affected, and in what way, varies greatly. Approximately 60% of people born with SMA are diagnosed with the most severe form of the condition, SMA type 1. Without treatment, these babies rarely live past their 2nd birthday.

The UK have introduced three new disease modifying treatments over the last seven years which are clinically proven to halt the progression of the disease with reserach showing that 95% of motor neurons are lost during the first 6 months. Although the treatments are highliy effective, they do not repair any damage to the nerves or the muscles that has been caused by disease progression. Therefore, clinicians rely on recognition of symptoms before treating the condition, in many cases, it is already too late to see the best outcomes possible. You can read more about this in the ‘Every Moment Matters Report’ [Newborn Screening for SMA – SMAUK](https://smauk.org.uk/advocacy-and-campaigning/newborn-screening/).

**Why screening is necessary**

If treated pre-symptomatically, babies with SMA can grow up following relatively normal developmental patterns[[1]](#footnote-2). If treated after symptoms have started, people with SMA will need to live managing varying complex needs including the need for a powered wheelchair, tube feeding, reliance on bi-pap ventilation as well as severe scoliosis and kyphosis.

***Insert your personal story here, including your current needs or the needs of your child (if you want to).***

**What is happening now?**

In 2018, the UK Newborn Screening Committee (UK NSC) unanimously rejected the opportunity for SMA to be included on the existing blood spot test due to a lack of clinical efficacy and safety data. Now, severn years later, there is a significant amount of clinical and real-world data available and SMA is currently being reassessed by the UK NSC.

At the UK National Screening Committee meeting in June 2023, the committee recommended that a new economic model would be commissioned and that work to scope an ‘in service evaluation’ (ISE) of newborn screening for SMA should be conducted at the same time.

An in-service evaluation is like a pilot study and will help the UK NSC develop UK specific evidence on newborn screening for SMA and understand how it might work in a UK setting. This will inform the committee’s final recommendation on whether SMA is added to the UK newborn screening programme and heel prick test.

After prolonged and frustrating delays, the National Institute for Health and Care Research (NIHR) has finally issued a call for research to identify a team for the SMA ISE project. While this is a welcome step forward, the projected start date for the research team is not until September 2026. This means it could be towards well into 2027 before the first baby in England is screened for SMA. These unconscionable delays will have a profound and devastating impact on the quality of life for countless babies born with SMA and their families, continuing to deny them the life-changing benefits of early diagnosis and intervention.

In addition, the current plan for the In-Service Evaluation (ISE) would see only 60% of babies born in the UK screened for SMA. This would create a deeply concerning postcode lottery, leading to significant inequities in treatment outcomes. Tragically, some children born with SMA will face a life with complex needs, including reliance on tube feeding, respiratory support, and severe mobility struggles, while others, simply by virtue of their birthplace, will have the chance to live healthy lives and follow normal developmental patterns, thanks to early diagnosis and intervention. This disparity is unacceptable for the SMA community.

**The impact of delaying newborn screening**

Studies have estimated that newborn screening for SMA will provide annual cost savings of approximately £62 million 3. Based on this model, delaying the introduction of the ISE by two years could mean the NHS is obliged to pay another £134 million managing the condition for the annual cohort over that two year period.

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With such stark evidence showing the transformational effects of the disease modifying treatments for SMA, available both in the UK and across the world, it is unethical to delay the implementation of a UK wide ISE any longer. The NHS is paying huge amounts of money for these drugs, administered after symptoms are seen, and then must pay even more for the management of an individual's complex needs over their lifetime.

As The UK is lagging behind the rest of the world in newborn screening with 66% of babies now being screened for SMA in wider Europe[[2]](#footnote-3), including in Ukraine, where it was considered so crucial that a newborn screening programme was established during a war. In 2024, Republic of Ireland, Luxembourg, Slovakia and Greece added SMA to their newborn screening programmes. In the US, all states now have NBS implemented.

**The Lancet letter**

On February 7th 2025, a letter authored by leading SMA clinicians, Laurent Servais, Tamara Dangouloff, Francesco Muntoni, Mariacristina Scoto and Giovanni Baranello, entitled ‘[Spinal muscular atrophy in the UK: the human toll of slow decisions](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(25)00048-0/fulltext)’ was published in the prestigious scientific magazine ‘The Lancet’. 3

The letter highlights the ‘*substantially different outcomes for children born in the UK compared with those born in many other countries where newborn screening is available’*. The authors powerfully describe some shocking statistics on the differences seen in the outcomes for babies born with SMA type 1 in the UK when compared to those in Europe, who are being diagnosed and treated through newborn screening.

They explain how in the UK, babies born with SMA, treated after symptoms start, are still dying. Of those born with SMA type 1 who live, non can walk and the majority are reliant on ventilatory support and tube feeding. Comparatively, in Belgium, babies diagnosed and treated through newborn screening all survived, all are ambulant, and none are reliant on ventilatory or nutritional support.

**How you can help**

As a family living with SMA within your constituency, we hope that you will support us by raising awareness of our two asks within parliament:

1. **The UK National Screening Committee fast tracks the implementation of the ISE for newborn screening for SMA.**
2. **The ISE for newborn screening for SMA is UK wide, ensuring every baby born in the UK is screened for SMA, reducing the current health inequities within the SMA landscape.**

I look forward to hearing your response in due course.

Yours Sincerely

***Insert name***

<https://www.zolgensma.com/zolgensma-studies/presymptomatic-study-results>

1. <https://www.sma-screening-alliance.org/map>
2. <https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(25)00048-0/fulltext>

1. [↑](#footnote-ref-2)
2. [↑](#footnote-ref-3)