

Subject: Constituent Urgent Request: Please attend a Parliamentary Debate on Newborn Screening for SMA on Monday 22nd June 2026.

Dear **[MP Name]**,

I am writing to you as one of your constituents to ask for your urgent support regarding a matter of life-changing importance.

The singer Jesy Nelson, a Patron of SMA UK, recently launched a petition calling for the UK Government to fund and fast-track the addition of Spinal Muscular Atrophy (SMA) to the NHS newborn heel-prick test. This petition has received overwhelming public support, amassing over 149,000 signatures.

As the 100,000-signature threshold has been surpassed, we are delighted that the petitions committee have agreed to schedule a debate, opened by Lewis Atkinson MP,

The debate will take place on:

Monday 22nd June at 6pm in Westminster Hall.

My Request: I urge you to use your voice and attend the debate urging the government to fast-track the rollout of the In-service Evaluation (ISE) and ensure no baby in England is left behind.

The Current Gap: Current plans for an ISE in England are scheduled to begin in October 2026 however will only include 72% of the country. This leaves approximately 163,000 babies (28%) without screening until potentially 2030 or 2031. We have spoken to the Health Secretary's team, who are looking at moving faster, but we need parliamentary pressure to ensure this happens.

How SMA has impacted my life: *[USE THIS SECTION TO ADD YOUR PERSONAL STORY. For example: Are you a parent of a child with SMA? Are you living with SMA yourself? Did a late diagnosis affect the treatment options available? Sharing your specific experience helps the MP understand the human cost of the current screening delays.]*

Why urgent action is needed:

- Every year in the UK, 48 babies are born with Spinal Muscular Atrophy with 60% of those having the most severe form, SMA Type 1.
- There is clear evidence, both in the UK and across the world, that babies who are diagnosed and treated before symptoms appear have significantly better health outcomes. Many can meet developmental milestones that would not have been possible without early intervention.
- Once symptoms begin, damage to motor neurons cannot be undone.
- The UK has three effective treatments for SMA, but timing is everything. This is why newborn screening is so important. Time is neurons!
- Screening allows SMA to be identified in the first weeks of life, often before any signs are visible, giving families and clinicians the opportunity to act quickly, start treatment early, and give babies the best possible chance to thrive.

I look forward to your response.

Yours sincerely,

[Your Full Name] [Your Full Address & Postcode] [Your Phone Number]