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How have you been involved with SMA?

For several years, I ran the UK SMA Newborn Screening Alliance, a coalition of academics, clinicians and patient organisations with a shared interest in the introduction of newborn screening in the UK at the earliest opportunity. The Alliance was jointly hosted by the patient organisations SMA UK and MDUK, and chaired by Professor Laurent Servais, an eminent professor of paediatric neuromuscular diseases and SMA NBS advocate.

What did this involve in practice?

The Alliance worked together to push for newborn screening to be introduced at the earliest opportunity – raising the profile of this topic and creating pressure for change. This involved a wide range of activities from developing messages and materials to explain why introducing newborn screening was needed urgently, to engaging with parliamentarians and the UK National Screening Committee.

What do you think of the recent news?

I am beyond delighted that we are making tangible progress in England and Scotland to getting newborn screening for SMA in the UK. This development will be lifechanging for so many families in the future. I am so grateful for all the people in the SMA community who have campaigned for this outcome relentlessly for many years. The resilience and commitment of SMA UK and MDUK and the patients they represent was at the heart of the campaign from the start and it is the human side of this story that had the power to secure a positive decision.

What can we learn for the future?

The job is still not finished – we need to rapidly move to eliminating inequality across the UK and ensure that Wales and Northern Ireland can provide newborn screening for SMA as soon as possible. We need a formal and final decision to add SMA to the UK newborn screening programme.

It is also important that there is a full review of what has and hasn't worked well in the process so far. We must keep our eyes on the future and ensure that we do everything we can to deploy screening where it will make a difference as fast as we can.