Press release: National pathway for SMA seeks to save children's lives
For release on Tuesday 11th May 2021

In the UK, 65 babies are born every year with spinal muscular atrophy (SMA), and 60% of these will have the most severe form of SMA - type 1 - affecting the child before they are six months old.

Neuromuscular function is lost from the point of onset - meaning that the more quickly the condition is diagnosed and treated, the more function the child can retain. With type 1, early recognition and treatment can mean the difference between life and death.

Until recently, there was no treatment. A diagnosis could mean significant disability for the child, or even loss of life through breathing difficulties. The only support available for a baby diagnosed with SMA type 1 was palliative care.

Now, however, early diagnosis and prompt access to treatment can mean a complete halt to progression - and the earlier that treatment comes, the more function the child retains, and the better their quality of life, and the lives of their family.

This incredible chance at life is dependent on non-specialists such as GPs, health visitors, maternity staff and neonatal nurses noticing the signs and symptoms of the condition. Unfortunately, there has been insufficient education around these 'red flags' that might indicate there is a problem, or what to do if they are spotted.

In response to this need, a group of professionals have come together to develop a paediatric SMA pathway, to provide that education and information, and to save the lives of children born with SMA. The pathway development has
been sponsored by Biogen Idec who have had no control over the educational content of this activity.

Fig 1: The overview page for the SMA pediatric national pathway

The core goals of the pathway are to:

- increase professional awareness of SMA
- improve earlier recognition and referral for diagnosis
- Raise awareness of the new progression halting treatments available for SMA
- Highlight the care infants, children and adults require from specialist and generalist services

Portia Thorman, mother to Ezra who is 4 years old and lives with SMA type 1, said:

'Ezra was 5 weeks old when he caught a cold. He was hospitalised and intubated for days. A nurse commented on his tone but it was dismissed. A few weeks later he began to lose his grasp, his arm movement. He had
no head control, no weight bearing. His legs went floppy. The doctors said it was because he had been ill.

He was 4 months old before we got a diagnosis. If it had been picked up at 5 weeks, when we were first admitted, Ezra's life - all our lives - could look so different.'

Sue Thomas, healthcare consultant and pathway facilitator, said:
'There is no cure for SMA to date, and until recently there were no treatments either. However, the range of new treatments now present progression-halting opportunities for infants and children.

It's vitally important that there is universal awareness of these groundbreaking treatments. Many infants may experience delays in being referred for assessment and diagnosis of SMA but we hope that by making the clinical pathway more explicit this will raise awareness of SMA and the fact that something can now be done to delay progression.'

Sarah Gillett, Managing Director of Neurology Academy said,
'Our mission is to provide transformational education so that individual's lives are improved. I don't think any education could be more transformative than that which saves lives - and which gives infants, young children and their families the best possible life together

Access the full pathway here or watch a short animation about why the pathway is needed, and what 'red flags' to watch for, to ensure prompt referral, diagnosis and treatment for babies with SMA Type 1.
About Neurology Academy
Neurology Academy is an innovative educational provider for healthcare professionals including consultants, specialist nurses, pharmacists, therapists and other allied health professionals. Our courses are developed by practicing specialists who combine their experience and expertise into case-based learning designed to create specialists in their field with confidence in effecting change.

We specialise in education, networking and mentorship across a range of conditions, each of which has its own 'Academy', of which MS Academy is one.

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The Spinal muscular atrophy paediatric pathway has been sponsored by Biogen Idec. Biogen Idec has had no control over the educational content of this publication.