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MPs to debate new drug after young Heidi denied treatment

By [Heather Large \(/news/authors/heather-large/\)](/news/authors/heather-large/) | [Health \(/news/health/\)](/news/health/) | Published: Jul 6, 2019

An MP has welcomed the offer of a parliamentary debate over a new drug for a rare muscle-wasting disease after it emerged one of her constituents may not be eligible for treatment.



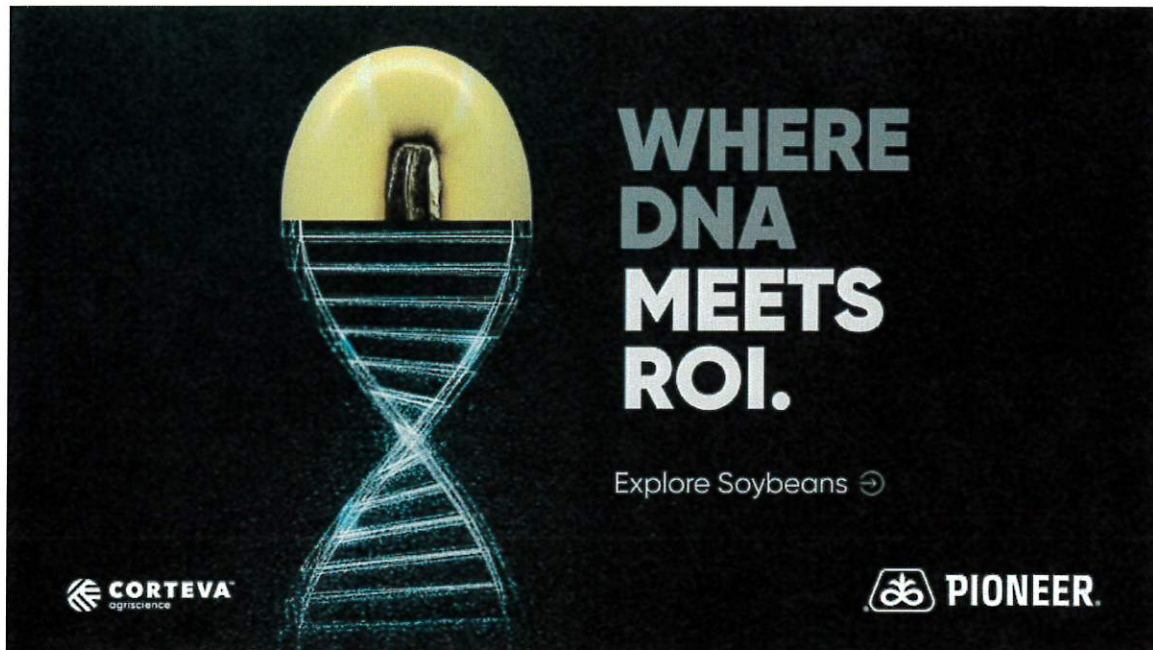
Heidi Prescott-Booth with her mum Katie

Heidi Prescott-Booth, who is just 11, has spinal muscular atrophy (SMA) – a genetic condition that makes muscles weaker and causes problems with walking and movement.

She has been campaigning for the only known treatment - Spinraza - to be made available on the NHS and was over the moon when it was approved in May.

But Heidi has been left heartbroken (<https://www.expressandstar.com/news/2019/06/19/heidi-heartbroken-as-new-drug-is-refused/>) after finding out she may not qualify to receive it because she can no longer walk the required five steps.

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The advertisement features a central image of a glowing yellow lightbulb with a DNA double helix structure below it, set against a dark background. To the right of the image, the text reads "WHERE DNA MEETS ROI." in large, bold, white letters. Below this text is a link "Explore Soybeans" with a right-pointing arrow icon. In the bottom left corner, the Corteva Agriscience logo is displayed, and in the bottom right corner, the Pioneer logo is displayed.

Wolverhampton South West MP Eleanor Smith has now written to the National Institute for Health and Care Excellence (NICE) and is calling for the drug to be made available to all.



Eleanor Smith, Katie Prescott and her daughter Heidi. Credit: Kate Gilbert

While House of Commons Speaker John Bercow is giving MPs the chance to debate NICE's decision on access to Spinraza in Parliament before the summer recess, which has been welcomed by Heidi's mother Katie. It came after the issue was raised in the House of Commons by North East Somerset MP Jacob Rees-Mogg.

Ms Smith said: "The decision by NICE to restrict access to the drug Spinraza was grossly unfair to my young constituent Heidi, and all those other children and adults with SMA who have now been denied the one available drug known to slow the effects of SMA .

"To then mislead this group, by suggesting Spinraza would be available to all was despicable. To offer hope, then crush it, is a terrible thing to do.

Advertising

"I have written to NICE regarding their decision to limit access to the drug Spinraza. They have replied informing me that an appeal has been lodged against their decision, and this is now being reviewed. I am in agreement with the SMA charities lobbying NICE that there is no medical evidence Spinraza is not effective within the excluded population, and should be made available to all.

"Scotland has announced that from July 2019 Spinraza can be prescribed for those with SMA Types 2 and 3 as well as the original Type 1 cases. This is great news but we need his fairness and parity in England, Wales and Northern Ireland.

"This fight is not over. The offer by John Bercow, speaker of the house, to debate NICE's decision on access to Spinraza in Parliament before the summer recess is very welcome. We should do everything we can to reverse NICE's decision and I am consulting with the charity SMA UK to plan the best way forward.

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"Of course Jacob Rees-Mogg was correct to point out NICE has been misleading about which people with SMA could get Spinraza. When NICE says something they should be held to account and made to do it."

There are different types of SMA ranging from very severe type 1 through to type 4 – Heidi has type 3 – and one in 40 people carry the gene.

It is estimated there are there are between 600 and 1200 children and adults in the UK living with SMA.

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