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Department of Health and Social Care <donotreply@dhsc.gov.uk>
To: "Ilyashenko, Gennadiy" <gennadiy.ilyashenko@treatsma.uk>

29 January 2019 at 10:51

Our ref: DE-1162476

Dear Dr Ilyashenko,

Thank you for your further correspondence of 8 January to Matt Hancock about nusinersen (Spinraza) for the treatment of spinal muscular atrophy (SMA). I have been asked to reply.

I appreciate your continuing concerns about this issue.

I am afraid there is little I can add to the Department's replies of 9 October and 12 November (our refs: DE-1147969 and DE-1152941). You may be interested to know that the National Institute for Health and Care Excellence (NICE) recently published an update, advising stakeholders that it has held further discussions with Biogen, the manufacturer of nusinersen. These discussions have focused on how the company can respond to concerns raised by NICE's independent appraisal committee. It is important to note that such discussions are between NICE, NHS England, and Biogen, and need to be held without Government interference.

I hope that this reply provides some assurance that the appraisal process is still ongoing and that NICE will fully consider the comments made in response to its recent consultation.

Yours sincerely,

Tamsin Spargo
Ministerial Correspondence and Public Enquiries
Department of Health and Social Care

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