

Ms Catherine Woodhead  
Muscular Dystrophy UK

Mr Doug Henderson  
Spinal Muscular Atrophy UK

Mr Gennadiy Ilyashenko  
TreatSMA

6 December 2018

Dear Ms Woodhead, Mr Henderson & Mr Ilyashenko,

Thank you for your letters dated 29 November and 4 December 2018.

I understand your concern and frustration in relation to the closure of the EAP program by Biogen on 1 November 2018.

I'm afraid it is not for NICE to agree any bridging solutions in this context; such arrangements, if it deemed appropriate, must come from Biogen and agreed with NHS England. We have in the course of our discussions asked Biogen to consider options that would enable access while the technology appraisal process is being undertaken.

NICE and Biogen remain committed to continuing to progress discussions. Both organisations are working together and with others to ensure all outstanding questions and queries are addressed. A timeline for the next discussion has yet to be agreed and we will communicate an update in due course.

Yours sincerely

**Sheela Upadhyaya**

Associate Director, Highly Specialised Technologies & Technology Appraisals  
Centre for Health Technology Evaluation  
National Institute for Health and Care Excellence