

Terry O'Regan
Vice President and Managing Director
Biogen UK and Ireland

29th November 2018

Dear Mr O'Regan,

Access to nusinersen discussions with NICE and NHS England

We are contacting you following NICE's announcement on 12th November that they are continuing to progress discussions with Biogen and their assurance that they are committed to swiftly progressing these discussions with both Biogen and NHS England.

We are encouraged that you and NICE are working on potential routes around the cost-effectiveness calculations which have appeared to be a significant barrier in the process so far. We hope that these discussions can be conducted in parallel with negotiations with NHS England on reimbursement and understand that the negotiations are at a delicate stage.


However, you will no doubt be aware that there are already at least two babies with a new diagnosis of SMA Type 1 who have not been able to access nusinersen treatment due to Biogen's decision to close the EAP on 1st November. The health of these infants will decline because of this and the delay in the process for evaluating this drug. Tragically, even if the drug is made available in the future, the fact that there has been an avoidable delay means that there will be a worse outcome.

As patient groups we cannot stand by while families endure the distress that this brings and watch clinicians having to deliver this devastating news without contacting you, NICE and NHS England. We therefore ask that, as an act of 'good faith' in the commitment of all parties to progress discussions to a satisfactory conclusion, you all agree with immediate effect to implement a 'bridging solution' for these and any other infants with SMA Type 1.

This request is also being made to John Stewart - National Director of Specialised Commissioning, NHS England - and Sheela Upadhyaya - Associate Director Technology Appraisals and Highly Specialised Technologies, NICE - with copies to our clinical colleagues, Professor Francesco Muntoni and Dr Ros Quinlivan.

We look forward to your earliest possible reply to our request and thank you for your continued efforts in this difficult process.

Yours sincerely,



Catherine Woodhead
Chief Executive
Muscular Dystrophy UK



Doug Henderson
Managing Director
Spinal Muscular Atrophy UK



Gennadiy Ilyashenko
Co-founder TreatSMA