Your Address Here

NAME AM
Northern Ireland Assembly
Parliament Buildings
Ballymiscaw
Stormont
Belfast
BT4 3XX

Dear xxxx

I am writing to you as a constituent regarding access to nusinersen: a new treatment for spinal muscular atrophy (SMA).

SMA is a rare inherited neuromuscular condition affecting the lower motor neurons. SMA may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. SMA Type 1 is the most severe form of SMA. Accounting for between 50 – 70% of cases of childhood onset SMA, for the majority of children (approximately 95%) life expectancy is under 2 years.

You could include information about your own connection to spinal muscular atrophy and the importance of access to treatment. Please remove if you like.

The Food and Drug Administration (FDA) in the United States recently approved nusinersen for use across the range of spinal muscular atrophy patients – allowing it to be marketed for SMA Types 1, 2 and 3. This is a landmark decision: nusinersen is the first drug for spinal muscular atrophy to receive approval from a regulator. We understandt he drug has been shown in clinical trials to improve motor function in SMA patients to a clinically significant degree.

We are very concerned that the drug is not yet available in Europe. It is vital that approval is given by regulators at the European Medicines Agency (EMA). That way, the process for reviewing the drug in the UK can begin. The timing of this decision is crucial: for many patients, life expectancy is so limited a prolonged decision could be a matter of life and death.

I am therefore writing to ask if you will contact the Executive Director at the EMA – Professor Guido Rasi - to urge him and his colleagues to expedite the review of nusinersen, given the severity of SMA and the urgent need for treatment.

Professor Rasi can be contacted at:

European Medicines Agency
30 Churchill Place
Canary Wharf
London E14 5EU
United Kingdom

If you require any further information – or a suggested letter to send to Professor Rasi – please contact Peter Sutton on 020 7803 4838 or email p.sutton@musculardystrophyuk.org.

Thank you for taking the time to consider the request posed in this letter. I look forward to hearing from you shortly.

Yours sincerely,

YOUR NAME