Spinal Muscular Atrophy Support UK
Help for today • Hope for tomorrow
Established in 1985

Muscular Dystrophy UK
Fighting muscle-wasting conditions

TreatSMA

The SMA Trust
Dedicated to finding a cure and treatments for Spinal Muscular Atrophy

To: Terry Oregan (Vice President & Managing Director, Biogen UK and Ireland)
Alessandro Marcuzzi (Senior Director & Head of SMA Europe and Canada)
Caren Deardorf (Senior Director & Global Brand Lead)

16th May 2018

Dear Biogen,

Thank you for Biogen's latest UK community update following the publication of the Scottish Medicines Consortium recommendations about NHS Scotland's funding of nusinersen.

We were delighted to read that the committee heard '*compelling evidence on the benefits of nusinersen, supported by the views of experts and patient groups and was able to apply a very high degree of flexibility in accepting this medicine for type 1 SMA.'*

Thank you for Biogen's commitment to these children with your funding of the Expanded Access Programme for all this time and now with presenting such a strong case to the SMC. At last we can all rest assured that families will have access.

The committee went on to say, *"Unfortunately, the evidence presented suggested that nusinersen was substantially less cost effective when used in types 2 and 3 and therefore could not be accepted by the committee. These are incredibly difficult decisions. The medicine is extremely expensive and there is a need to consider all those who need treatment by NHS Scotland. We would welcome a resubmission from the company which addresses the issues raised."*

We know this is hugely disappointing for Biogen as well as for the community and, as we know from our submissions and the people we heard from, many families with children or young people and adults with SMA Type 2 or Type 3 will be devastated.

One of the barriers to access is likely to have been the assessment process itself and the delays with the Scottish Government's introduction of a new process for assessing ultra-orphan medicines as outlined in the Montgomery Report. We understand that this should have taken place by now. We are therefore urging members of the SMA community to write to their MSPs requesting that they contact the Cabinet Secretary for Health and Sport to ask that the recommendations are implemented urgently so that nusinersen can be reassessed for those with SMA Types 2 and 3 as soon as possible.

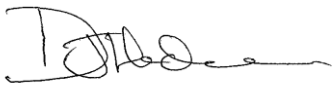
However, the statement by the SMC that "*the evidence presented suggested that nusinersen was substantially less cost effective when used in types 2 and 3"* and *"the medicine is extremely expensive*"

causes us great concern that, even with a new process, this will not be enough and that the barrier of price will remain.

In the many meetings we have had with Biogen representatives, they have often said Biogen "*will not let price be a barrier to access*". We have been impressed with your commitment to the SMA community and how much you have done thus far. We urge you to now continue with your firm commitment and review your pricing, be prepared to negotiate on price with the Scottish Medicines Consortium and NHS Scotland at the earliest opportunity, and resubmit as soon as possible.

It is essential that Biogen comes to an agreement on the price and funding model in the interests of patients and families, and, indeed, the company itself.

Yours sincerely,



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