

To the Commissioning Group

Thank you for the information about the NHS Birmingham and Solihull Clinical Commissioning Group: engagement on proposed changes to health policies.

We had a look at your questionnaire but found that it would not give us the opportunity to give the feedback we think necessary, hence this email.

### **Use of cough assist machines**

We have read in your '*What is coughing?*' advice that 'due to the lack of robust clinical evidence to support the use of cough assist machines as clinically effective intervention, cough assist machines are not routinely commissioned' *unless patients meet criteria you have listed*.

We are concerned to ensure that your criteria include routine funding of cough assist treatment for patients with spinal muscular atrophy who are 'non-sitters' or 'sitters'.

The references you have do not appear to include the new 2017 international standards of care for SMA that have been established by an international group of experts. These standards are described in Part 1, page 10<sup>1</sup> as '**assessments or interventions that constitute the *minimal care* that families should expect to find in any neuromuscular centre**'.

A summary of these *minimal care* interventions in terms of pulmonary care is outlined on Part 2, page 3<sup>2</sup> where you will see that cough insufflator / exsufflator is very clearly a recommended intervention for anyone with SMA who is either a non-sitter or sitter –this includes those with SMA Type 1 or SMA Type 2.

We are concerned that these patients should have routine access to cough assist machines and that this should be explicit. Their consultant should not have to prove exceptional clinical need.

We hope that you can reassure us that this clearly routine need will be reflected in your future policy.

1. Eugenio Mercuri, et al., Diagnosis and management of spinal muscular atrophy: Part 1 Recommendations for diagnosis, rehabilitation, orthopedic and nutritional care. *Neuromuscular Disorders* (2017), doi: 10.1016/j.nmd.2017.11.005  
[www.sciencedirect.com/science/article/pii/S0960896617312841?via%3Dihub](http://www.sciencedirect.com/science/article/pii/S0960896617312841?via%3Dihub)
2. Richard S. Finkel, et al., **Diagnosis and management of spinal muscular atrophy: Part 2: Pulmonary and acute care; medications, supplements and immunizations; other organs systems; and ethics**, *Neuromuscular Disorders* (2017), doi: 10.1016/j.nmd.2017.11.004  
[www.sciencedirect.com/science/article/pii/S0960896617312907?via%3Dihub](http://www.sciencedirect.com/science/article/pii/S0960896617312907?via%3Dihub)