

Friday 26th May 2023

To the JCVI Secretariat,

We are writing to express our disappointment at the lengthy process the Joint Committee on Vaccination and Immunisation (JCVI) have employed to reach a conclusion about not expanding access to the RSV vaccine, particular with children living with Spinal Muscular Atrophy (SMA) Type 1, the most severe case of the condition.

SMA UK has been corresponding with the JCVI since August 2022 advocating to expedite the decision to expand access to all under twos living with SMA Type 1.

Our asks echoed those of the NHS England Nusinersen SMA Clinical Panel, SMA Reach UK and the Onasemnogene National Multidisciplinary Team (NMDT), who also sent a request for the JCVI to consider the use of Palivizumab for RSV prophylaxis in SMA1 early in 2022.

The response that we received from the JCVI on 19th August 2022 stated;

‘The aim is to get an outcome on this ahead of the coming winter when RSV transmission tends to be highest’.

The committee did not reach a conclusion in time for the 2022 RSV season, a longer than usual season which was particularly difficult for many babies and children living with SMA. Public health officials warned in summer 2021 that the lower levels of infection the previous winter (due to shielding during the COVID pandemic) meant many children would not have developed immunity to RSV¹. Furthermore, the report ‘Covid19: Preparing for the future’ published in July 2021 by the Academy of Medical Sciences called for the NHS to;

‘...develop plans for increased paediatric ICU capacity and for much greater access to the monoclonal antibody pavalizimab to manage this potential large outbreak this winter. The introduction of multiplex testing (at least for SARS-CoV-2, RSV and influenza) will be important for managing febrile children in the coming winter, as well as for vulnerable adults...’²

Yet the JCVI still failed to expedite a decision that would protect those young children and babies most at risk.

In the reply to our correspondence, Jonathon Croft, the scientific secretariat to the JCVI told us in August 2022 that:

‘Specialised Commissioning at NHS England is fully aware of this issue and I understand there has been work going on looking at this issue in terms of the scientific/clinical evidence’

and stated: ***‘I understand the intention is to have an outcome as quickly as possible’.***

SMA UK’s correspondence with the JCVI over the past year has been shared publicly with the SMA community on our website. Many families of children living with SMA type1 have had their expectations

¹ <https://lordslibrary.parliament.uk/respiratory-syncytial-virus-and-its-impact-on-the-nhs/>

² COVID-19: Preparing for the future Looking ahead to winter 2021/22 and beyond 15 July 2021 3.2.2

raised for access in 2022. We are now approaching the 2023 RSV season with no hope for eligibility being extended.

In the latest correspondence from the JCVI, SMA UK were informed that:

'The secretariat had received correspondence about young children with spinal muscular atrophy (SMA) type 1 who were considered to be at particular risk and potentially could be included in the eligible cohort based on clinical judgement but there was an obstacle in terms of the mechanisms for this and funding.'

What we are calling for

We feel our community deserve a more detailed explanation of these obstacles. One family that we support were advised by their specialist respiratory team that their son would benefit from the RSV vaccine due to his respiratory compromise. But because he is not reliant on overnight ventilation, he was not considered eligible. So, to keep him safe and to avoid hospitalisation, the family resorted to fundraising to pay for Palivizumab, which cost them £8,000 per year for the first two years of their son's life.

If the JCVI were willing to increase transparency, consult with patient advocacy groups and specialist clinicians through all stages of the assessment process, we could work together to remove some of these obstacles. Considering real world evidence for rare diseases (as NICE currently does) would give the JCVI a deeper understanding of the impact and cost to the NHS of RSV on high-risk groups and would highlight how widening access this year would bring both health and economic benefits.

We were pleased to see the new RSV vaccine, Nirsevimab is now being considered for a universal vaccination programme next year and the recommendation for eligible high-risk groups to receive the new vaccine this winter is very sensible.

SMA UK engage with a large proportion of the SMA community, on our database we have 57 under twos living with SMA type 1 in the UK. Denying this relatively small number of children access to the new vaccine this year, ignoring timely evidence from specialist clinicians, patient advocacy groups and individual parent advocates appears irresponsible and, in many cases, may result in expensive & possibly traumatic hospitalisation including invasive ventilation and treatment in critical care.

The UN convention of the rights of the child states;

'Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.'

Therefore, we urge the JCVI to reconsider their position and work to ensure access to Nirsevimab for all under twos living with SMA type 1, to protect them for the 2023/2024 RSV season.

Yours sincerely



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