

Llywodraeth Cymru Welsh Government

Ein cyf/Our ref:WQ89870

Natasha Asghar MS Senedd Regional Member South Wales East

Natasha.Asghar@senedd.wales

18 December 2023

Dear Natasha

Thank you for your recent written question asking me to provide assurances that children aged 2 to 5 with cystic fibrosis will have full and permanent access to treatment now and in the future on the NHS in Wales, following the Medicines and Healthcare products Regulatory Agency's decision to extend the licence of Kaftrio?

The cystic fibrosis treatments Kaftrio, Symkevi, Orkambi and Kalydeco are all routinely available in Wales for their licensed indications in accordance with a four-year commercial access agreement reached between the Welsh Government and the manufacturer, Vertex Pharmaceuticals in 2020. This includes the recent license extension authorising use of Kaftrio in children aged 2 to 5 years.

A condition of that agreement was that Vertex would engage with a National Institute for Health and Care Excellence (NICE) appraisal of Kaftrio, Symkevi and Orkambi in order to determine the effectiveness of these treatments and ensure they were in fair balance with the price paid by the NHS.

At the end of the appraisal process, should NICE not recommend the use of these treatments it will not affect anyone currently receiving them or anyone who commences treatment ahead of NICE's final recommendation, this includes children who commence treatment with Kaftrio in accordance with the license changes which came into effect earlier this month allowing eligible children aged as young as 2 years of age to receive treatment.

Yours sincerely

M. Z. Maja

**Eluned Morgan AS/MS** Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

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We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.