

24 May 2016

Vaughan Gething AM
Cabinet Secretary for Health & Social Services
National Assembly for Wales
Cardiff Bay
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Dear Secretary,

Congratulations and request for a meeting from the Cystic Fibrosis Trust

I wanted to extend a warm welcome to you in your new role as Cabinet Secretary for Health & Social Services.

There have been many positive developments in Wales for people with cystic fibrosis in recent times; funding in principle for a much-needed new CF centre in Llandough, access to the gene-specific cystic fibrosis treatment Kalydeco for the majority of people eligible for it, and the introduction of the soft opt-out system for organ donation, which is already showing promising results.

However, there are issues that need urgent attention: despite an extension to the license to Kalydeco for treatment of further mutations of cystic fibrosis being agreed in Wales in December 2015, and the fact that patients in England with these mutations have been on the treatment since July 2015, the 3 people eligible for it in Wales are yet to receive it. It is completely unacceptable that patients should be made to wait for this life-changing treatment, risking serious deterioration in their condition in the process.

Furthermore, and as you will be aware, the new cystic fibrosis treatment Orkambi is currently being appraised in England by NICE and is yet to begin the process for consideration by the All Wales Medicine Strategy Group. With an agreement in Wales likely to take some time, it is essential that patients deemed by their clinicians to be in a critical condition be given access for compassionate use to a treatment clinically proven to halt the progression of the disease.

However, clinicians have contacted us to raise strong concerns that their patients are running out of time to benefit from Orkambi, because the Welsh Health Specialised Services Committee (WHSCC) is yet to approve it for compassionate use.

I would be very grateful if you could look into these issues as a matter of urgency and if we could meet to discuss how we can work together.

I look forward to hearing from you.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'James Barrow', written in a cursive style.

James Barrow
Head of External Affairs