

# Cystic Fibrosis a fight we must win

Janet Finch-Saunders AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
CARDIFF  
CF99 1NA

3 June 2019

Dear Ms Finch-Saunders,

Thank you for your continued work in raising the issue of access to Orkambi, Symkevi and other cystic fibrosis medicines. The Cystic Fibrosis Trust is dismayed that access to these medicines has not been resolved.

It has been eighteen months since a petition was first submitted to the Assembly, followed by eight committee meetings. Yet due to continued disagreement between Vertex Pharmaceuticals, NHS Wales and the Welsh Government, people with cystic fibrosis are still waiting for access to these life-saving drugs. The impact of this delay is avoidable, irreversible health decline for people with cystic fibrosis in Wales.

Wales is a world-leader in cystic fibrosis outcomes, but this is changing. Recently, NHS Scotland and Vertex have reached an interim access deal through the PACS Tier 2 system, on the condition that Vertex submit Orkambi and Symkevi to the Scottish Medicines Consortium (SMC), and NHS England have recently made an offer based on a managed access scheme following the work of the Health and Social Care Select Committee in Westminster. Most notably, on Thursday May 30, Vertex Pharmaceuticals released headline results for their fourth cystic fibrosis medicine, which could radically transform the lives of nine in ten people with the cystic fibrosis in Wales

However, for people with CF and their families in Wales, the joy and optimism of these results was bitterly soured by the fear and anxiety that they will never get to use them. In the last three years, this issue has been debated three times in Westminster and not once in the Welsh Assembly. On 10 June access to cystic fibrosis medicines will once again be debated in Westminster Hall. However, there must be a Welsh solution that works for people in Wales with cystic fibrosis, whom without a forward process, are frustrated, angry, and distressed.

Will the Committee make an urgent suggestion that this issue is debated in the Assembly to shed light on these negotiations and push for a resolution?



David Ramsden  
**Chief Executive**