

# Cystic

# Fibrosis a fight we must win

David J Rowlands  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
CARDIFF  
CF99 1NA

22 January 2019

Dear Mr Rowlands,

The Cystic Fibrosis Trust is encouraged that a meeting has been scheduled between Vertex Pharmaceuticals and the AWTTTC. We hope that this will set the foundations for productive talks for an agreement to be reached that will enable people with cystic fibrosis in Wales to access new precision medicines.

Given the urgency of this matter, in the context of continuing deterioration of the health of people with CF in Wales who are eligible for these medicines and the more than three years of delay, an interim agreement must be implemented to ensure that immediate access can be provided while consideration continues. We are ready to support the Welsh Government in any way we can, and reiterate our willingness to advise the Welsh Government on how the UK CF Registry can support reimbursement decision making, as we recently were able to with the Scottish Government, where a pricing agreement has now been struck, allowing immediate access, and Vertex have committed to resubmitting to the Scottish Medicines Consortium.

Will the Committee make a further suggestion to the Cabinet Secretary to consider and agree a method of interim access as a matter of urgency now that these talks have resumed?

Yours sincerely,

David Ramsden  
**Chief Executive**