

# Cystic

# Fibrosis a fight we must win

Professor Mark Drakeford AM  
Minister for Health & Social Services  
National Assembly for Wales  
Cardiff Bay  
Cardiff CF99 1NA

11 May 2016

Dear Minister,

## **Orkambi – Compassionate Use in Wales**

It has been brought to our attention that clinicians are unable to prescribe Orkambi on compassionate use in Wales.

The treatment has been made available for compassionate use across the UK by the drug's manufacturer Vertex Pharmaceuticals and we know that it is being prescribed by clinicians in England, Scotland and Northern Ireland.

It is our understanding that 15 patients in Wales desperately need this treatment, including a 43 year old father of two who needs a lung and kidney transplant but has been rejected from two transplant lists because he is too ill. His only hope is to improve his lung function enough to survive a kidney transplant. Access to Orkambi on compassionate grounds is his only hope and time is running out.

I would be grateful if you could look into this as a matter of urgency and do everything in your power to ensure that patients, who are desperate and have nowhere else to turn, are given the opportunity to benefit from this treatment.

I look forward to hearing from you.

Yours sincerely,



**James Barrow**  
**Head of External Affairs**  
[james.barrow@cysticfibrosis.org.uk](mailto:james.barrow@cysticfibrosis.org.uk)  
07891 250 600

Fighting for a *Life Unlimited*

**Cystic Fibrosis Trust** 2nd Floor, One Aldgate, London, EC3N 1RE  
020 3795 1555 [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk) [enquiries@cysticfibrosis.org.uk](mailto:enquiries@cysticfibrosis.org.uk)  
Patron: His Royal Highness The Prince of Wales, KG, KT, GCB, OM

Cystic Fibrosis Trust is registered as a charity in England and Wales (1079049) and Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE