

Cystic Fibrosis beatable

Mr Simon Stevens
Chief Executive
NHS England
Skipton House
80 London Road
London SE1 6LH

26 June 2017

Dear Mr Stevens,

ORKAMBI

Today hundreds have protested because too many people have been waiting far too long for access to Orkambi.

This drug, which has been shown to improve lung health, significantly reduce the frequency of exacerbations and extend life is now available in Ireland, France, Germany, Denmark, Austria, Luxembourg and the US, but importantly not to almost three thousand people with cystic fibrosis right here in England.

People have been waiting since October 2015 for access to a treatment that could have prevented them developing permanent lung damage, from which they will not recover. I am writing to ask you to do all in your power to change this situation now before yet more damage is done.

We have been pushing the drug's manufacturer, Vertex to make a bold offer and have asked them to put forward a substantive proposal for your consideration. We urge you to work with them to find a solution and we will happily facilitate any meetings between NHS England and Vertex to help move things forward.

Significant progress has been made in the treatment of cystic fibrosis and valued care is provided across the NHS, however, the median age of death is still only 28. The people we support are literally running out of time and we need your help - not just for Orkambi, but in finding a fair and sustainable method of reimbursement for the pipeline of future treatments that are on the way.

I look forward to hearing from you.

Yours sincerely,



David Ramsden
Chief Executive

Cc: Lord O'Shaughnessy, Parliamentary Under Secretary of State for Health; Nicole Mather, Director, Office for Life Sciences; John Stewart, Acting Director: Specialised Services, NHS England.

Fighting for a *Life Unlimited*

Cystic Fibrosis beatable

Andrew Goodall
Chief Executive, NHS Wales
Public Health Wales
2 Capital Quarter
Tyndall Street
Cardiff CF10 4BZ

26 June 2017

Dear Mr Goodall,

ORKAMBI

Today hundreds have protested because too many people have been waiting far too long for access to Orkambi.

This drug, which has been shown to improve lung health, significantly reduce the frequency of exacerbations and extend life is now available in Ireland, France, Germany, Denmark, Austria, Luxembourg and the US, but importantly not to over 100 people with cystic fibrosis in Wales.

People have been waiting since October 2015 for access to a treatment that could have prevented them developing permanent lung damage, from which they will not recover. I am writing to ask you to do all in your power to change this situation now before yet more damage is done.

We have been pushing the drug's manufacturer, Vertex to make a bold offer and have asked them to put forward a substantive proposal for your consideration. We urge you to work with them to find a solution and we will happily facilitate any meetings between NHS Wales and Vertex to help move things forward.

Significant progress has been made in the treatment of cystic fibrosis and valued care is provided across the NHS, however, the median age of death is still only 28. The people we support are literally running out of time and we need your help - not just for Orkambi, but in finding a fair and sustainable method of reimbursement for the pipeline of future treatments that are on the way.

I look forward to hearing from you.

Yours sincerely,



David Ramsden
Chief Executive

Cc: Dr Frank Atherton, Chief Medical Officer; Dr Sian Lewis, Welsh Health Specialised Services Committee; and, Vaughn Gething AM, Cabinet Secretary for Health, Wellbeing and Sport.

Fighting for a *Life Unlimited*

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

Cystic Fibrosis beatable

Paul Gray
Director-General Health and Social Care
& Chief Executive of NHS Scotland
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

26 June 2017

Dear Mr Gray,

ORKAMBI

Today hundreds have protested because too many people have been waiting far too long for access to Orkambi.

This drug, which has been shown to improve lung health, significantly reduce the frequency of exacerbations and extend life is now available in Ireland, France, Germany, Denmark, Austria, Luxembourg and the US, but importantly not to around 250 people with cystic fibrosis in Scotland.

People have been waiting since October 2015 for access to a treatment that could have prevented them developing permanent lung damage, from which they will not recover. I am writing to ask you to do all in your power to change this situation now before yet more damage is done.

We have been pushing the drug's manufacturer, Vertex to make a bold offer and have asked them to put forward a substantive proposal for your consideration. We urge you to work with them to find a solution and we will happily facilitate any meetings between NHS Scotland and Vertex to help move things forward.

Significant progress has been made in the treatment of cystic fibrosis and valued care is provided across the NHS, however, the median age of death is still only 28. The people we support are literally running out of time and we need your help - not just for Orkambi, but in finding a fair and sustainable method of reimbursement for the pipeline of future treatments that are on the way.

I look forward to hearing from you.

Yours sincerely,



David Ramsden
Chief Executive

Cc: Shona Robison MSP, Cabinet Secretary for Health & Sport.

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

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Ms Valerie Watts
Chief Executive of the Health and Social Care Board for Northern Ireland
Public Health Agency
Linenhall Street Unit
12-22 Linenhall Street
Belfast, BT2 8BS

26 June 2017

Dear Ms Watts,

ORKAMBI

Today hundreds have protested because too many people have been waiting far too long for access to Orkambi.

This drug, which has been shown to improve lung health, significantly reduce the frequency of exacerbations and extend life is now available in Ireland, France, Germany, Denmark, Austria, Luxembourg and the US, but importantly not to over 100 people with cystic fibrosis in Northern Ireland.

People have been waiting since October 2015 for access to a treatment that could have prevented them developing permanent lung damage, from which they will not recover. I am writing to ask you to do all in your power to change this situation now before yet more damage is done.

We have been pushing the drug's manufacturer, Vertex to make a bold offer and have asked them to put forward a substantive proposal for your consideration. We urge you to work with them to find a solution and we will happily facilitate any meetings between the Health and Social Care Board and Vertex to help move things forward.

Significant progress has been made in the treatment of cystic fibrosis and valued care is provided across the NHS, however, the median age of death is still only 28. The people we support are literally running out of time and we need your help - not just for Orkambi, but in finding a fair and sustainable method of reimbursement for the pipeline of future treatments that are on the way.

I look forward to hearing from you.

Yours sincerely,



David Ramsden
Chief Executive

Fighting for a *Life Unlimited*

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Mr Simon Lem
Vice President, Regional General Manager
North Europe Vertex Pharmaceuticals (Europe) Ltd
Level 8
5 Merchant Square
Paddington
London W2 1AS

26 June 2017

Dear Mr Lem,

ORKAMBI

Today hundreds have taken to the streets to protest for Orkambi. Thousands have also signed a petition calling on Vertex to "make Orkambi affordable for the NHS" as too many people have been waiting for far too long and we need your help to change this.

We recognise that developing drugs like Orkambi takes significant investment, however, it is vital that they are not priced beyond the reach of public health services and only you can change this.

We note the progress that has been made in other countries and urge you to put forward a bold and substantive offer to NHS England, NHS Health Scotland, NHS Wales and Health and Social Care in Northern Ireland so that people in the UK are not left behind. We have asked the public health services across the UK to work with you to reach an agreement, but we need your help to make it happen.

We need a solution now, not only for Orkambi, but for future treatments too as every day that passes is a day where people are missing out on a treatment that could have a significant impact on their lives.

I look forward to hearing from you.

Yours sincerely,



David Ramsden
Chief Executive