

HEIDI ALLEN MP and IAN AUSTIN MP
SOUTH CAMBRIDGESHIRE and DUDLEY NORTH



HOUSE OF COMMONS
LONDON SW1A 0AA

Mr Michael Oliver
UK Country Manager for Vertex
Vertex Pharmaceuticals

Cc to – Mr Andrew Hollingsworth, Senior Manager Government Affairs & Public Policy, Vertex
Cc to – Lord O’Shaughnessy, Parliamentary Under Secretary of State for Health
Mr Simon Stevens, Chief Executive of NHS England

28th June 2018

Dear Mr Oliver,

We write to you as the voice of more than 10,000 sufferers of Cystic Fibrosis within the UK; whose families have contacted us requesting urgent access to the life-changing drug Orkambi pioneered and developed by your company, Vertex through over 21 years of research and dedication to this same cause.

We ask you to urgently resolve negotiations with NHS England that will result in access to this revolutionary drug. We understand that negotiations between NHS England and Vertex are ongoing and that the latest offer made by the NHS was considered by you to be ‘a good place to start’.

As you are acutely aware, Cystic Fibrosis robs sufferers of many things but perhaps most importantly time. Three years after Orkambi was licensed, CF sufferers are still waiting for access. Median life expectancy for CF patients is 47; if we set the negotiations in this context access to this drug has taken too long.

We recognise that Vertex have invested over 21 years of research and resource into developing this life-changing treatment; we understand that as a business you have a responsibility to seek a price that covers approved therapies and those in the pipeline. The conclusion of recent negotiations with the Swedish government demonstrated that a portfolio negotiation can be concluded for the benefit of patients.

However, when considering access to the larger UK CF population, we urge you to show some flexibility that allows for long-term development whilst giving patients short-term access to Orkambi. We seek reassurances that you are urgently invested in these negotiations; we want you and the NHS to hammer out an agreement that demonstrates your commitment as research scientists to improving the lives of people with CF.

A deal with NHS England gives Vertex access to real world evidence of CF, which will be of enormous benefit to your scientists working on the next generation of CF therapies. In conjunction with a fair deal for Orkambi this evidence base will allow Vertex to reach its goal of finding ways to treat the entire disease population.

We urge you to follow the leadership of your senior research fellow Fred van Goor when seeking a conclusion to the negotiations with the NHS - 'What is important is that patients get access to our medicines'. We couldn't agree more. Please make this happen without further delay.

Yours sincerely



Heidi Allen, MP



Ian Austin, MP

Alex Chalk, MP

Gordon Henderson, MP

Paul Farrelly, MP

Alex Sobel, MP

Helen Hayes, MP

Paul Sweeney, MP

Ann Clwyd, MP

James Frith, MP

Ronald Campbell, MP

Anneliese Dodds, MP

James Gray, MP

Rosie Cooper, MP

Ben Bradshaw, MP

Jeremy Lefroy, MP

Sandy Martin, MP

Ben Lake, MP

Jim Cunningham, MP

Sir Ed Davey, MP

Bim Afolami, MP

Jo Swinson, MP

Sir Jeffery Donaldson, MP

Bob Stewart, MP

Julia Lopez, MP

Sir Mike Penning, MP

Caroline Lucas, MP

Julian Sturdy, MP

Stephen Hepburn, MP

Dame Caroline Spelman, MP

Karen Lee, MP

Stephen Lloyd, MP

Dame Rosie Winterton, MP

Kate Green, MP

Stephen Morgan, MP

Darren Jones, MP

Kerry McCarthy, MP

Sylvia Hermon, MP

David Linden, MP

Layla Moran, MP

Teresa Pearce, MP

Emma Hardy, MP

Lisa Nandy, MP

Tim Farron, MP

Emma Little Pengelly, MP

Marie Rimmer, MP

Tom Brake, MP

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Matt Western, MP

Tonia Antoniazzi, MP

Gillian Keegan, MP

Nic Dakin, MP

Tulip Siddiq, MP

Oliver Letwin, MP

Nigel Dodds, MP

Vicky Foxcroft, MP

Alison McGovern, MP

William Wragg, MP

Ruth Cadbury, MP

Faisal Rashid, MP

Andrea Leadsom, MP

Ivan Lewis, MP

Gregory Campbell, MP

Jim Shannon, MP