Dr Reshma Kewalramani
Chief Executive Officer & President
Vertex Pharmaceuticals

2nd November 2022

Dear Dr Kewalramani,

It is now one year since we met with Vertex executives to discuss the gross inequality of access to lifesaving cystic fibrosis modulator drugs and to ask that your company live up to its human rights responsibilities by putting in place a comprehensive and effective global access plan.

Since that meeting almost nothing has changed. At the end of 2020 it is estimated that 12% of eligible patients were accessing Trikafta. It is still the case that only high income countries have reached reimbursement agreements with Vertex, meaning no patients in any low or middle income country have access to this lifesaving treatment. Based on epidemiological research, which includes estimates of undiagnosed patients, by academics Dr Andrew Hill and Jonathan Guo, this means that more than 50% of patients with CF - 82,000 people - are currently denied access to Trikafta.

None of the recommendations or requests we made in 2021 have been actioned despite your Executive Vice President, Amit Sachdev's reassurances that you were committed to looking at all the options. No tangible or consequential alternative steps to address the unacceptably low levels of CF treatment coverage across the majority of the world have been taken by your company.

Instead, we have spent the last year seeing members of our community, of the global CF community, dying without access. We have written to you begging for compassionate access to Trikafta for very sick patients, and seen those letters go ignored as our loved ones get sicker and die. In fact, your response has been to stop accepting new applications for compassionate access to Trikafta condemning more of the sickest patients to death. Thousands of cystic fibrosis patients have needlessly lost their lives since the creation and approval of a medicine that could have saved them.

It is clear that there is a deep and dark moral vacuum at the heart of your company, as you and a very small number of people get incredibly rich by creating false scarcity of a drug that could save the lives of thousands of people - many of them children - around the world. Your expected CF product revenues of $8.9bn in 2022 come at a very high price. We were dismayed to hear Vertex's Chief Financial Officer, Stuart Arbuckle's misleading comments on an investor call celebrating your financial success last week that only 'a small number of countries' are yet to reach a reimbursement agreement with you, when in reality the citizens of dozens of nations are still without access.

Your actions, holding the lives of patients to ransom to extract and maintain the highest possible price for Trikafta - $311,000 in the US - are all the more galling when we now know it could be profitably produced generically for less than $6000.

Anger is high in countries without access. But it is also growing in places where deals have been reached, such as Ireland, where CF clinicians last week accused Vertex of using vulnerable children as pawns to extract greater profit[1], and in the US where you recently announced that financial assistance for CF patients will be reduced in 2023.

So we write again to ask you to:

- Publish a comprehensive plan for universal access to CFTR modulators by the end of the year
- Drop all patent claims in low and middle income countries and commit to facilitating generic manufacturers seeking to supplying these markets
- Reach agreement with all high income country health systems to facilitate access within three months or accept that saving lives must be prioritised over Vertex profits through the facilitation of generic access.

These essential steps to bring an end to the immoral inequalities of access and avoidable deaths amongst the global cystic fibrosis community must be taken urgently, but having seen your company's inaction over the last year we have low expectations.

It is becoming increasingly clear that if we are to save our own lives and the lives of our children, our sisters and our brothers, our patients, then our community must take action ourselves to secure affordable access to CFTR modulator treatments. We will not rest until everyone, everywhere realises their right to access the cystic fibrosis medicines their lives depend on.

We look forward to hearing from you very soon with details of your plans to respond to this letter.

Yours,

Dr Cathy Baird, CF Clinician, South Africa
Sue Barnes, Vertex Save Us, UK
Marc Cotterill, Vertex Save Us, UK
Jolene Du Plessis, Vertex Save Us, South Africa
Rebecca Gameyel, Vertex Save Us, Lebanon
Prof. Nataliya Kashirskaya, CF Clinician, Russia
Prof. Bulent Karadag, CF Clinician, Turkey
Tanya Koorts, Vertex Save Us, South Africa
Gautam Kumar, Vertex Save Us, India
Rob Long, Vertex Save Us, UK
Diarmaid McDonald, Director, Just Treatment, UK
Belinda Nell, Vertex Save Us, South Africa
Elonet Opperman, Vertex Save Us, South Africa
Gayle Pledger, Vertex Save Us, UK
Tatiana Ramina, Vertex Save Us, Brazil
Rodrigo Rockenbach,Vertex Save Us, Brazil
Rida Viljoen, Vertex Save Us, South Africa

[1] https://www.irishexaminer.com/news/arid-40993547.html