November 10, 2022

Dear Dr. Bozic,

As directors of Cystic Fibrosis programs nationwide, we write to express our serious concerns on the upcoming changes to Vertex's copay assistance program. **We strongly urge Vertex to revise the 2023 program changes to ensure that no person with CF will experience an interruption in their life sustaining treatment and face the risk of significant clinical deterioration.**

We have heard from our patients and care teams that the 2023 changes to your copay assistance program are confusing, arbitrary, and time-consuming to navigate. We have had patients and families leave CF clinic in tears, worried how the increased costs will negatively impact their lives. Some individuals will almost certainly be forced to stop taking their modulators because they can no longer afford to do so, while others will be unable to navigate the administrative complexity; still more will forego other needed medications in order to ration funds to afford their modulator copay. This creates tremendous anxiety in the patient community that we support.

We are very concerned about the clinical harm to people with CF who lose access to CFTR modulator therapy. Within days of withdrawing from Ivacaftor, patients are at risk of experiencing a precipitous decline in health.[1] While there are no published case reports on the effects of withdrawal from elexacaftor-tezacaftor-ivacaftor (ETI) to date, there is preliminary evidence that significant clinical decline can occur. Two hospitalizations were reported to the CF Foundation Patient Registry within the last month associated with interruptions in ETI treatment: one after 7 days off therapy and the other after 25 days off therapy. Both individuals experienced a significant decrease in FEV1 with worsening cough and sputum production. Both were treated with intravenous antibiotic therapy. Although both patients have now restarted therapy with ETI and, though the long-term impacts of such a significant clinical event are yet unknown, it has been estimated that up to 50% of lung function loss is related to pulmonary exacerbations. These types of scenarios are dangerous, traumatic, and completely avoidable. We urge the medical leadership team at Vertex to consider the potential for harm that these copay assistance program changes will invariably cause for some individuals with CF who will face prohibitively high out of pocket costs.

The additional financial and administrative burdens due to the 2023 program changes will have significant negative effects on people with CF and their families. We know that patients skip medication doses or take less medication than prescribed when faced with an increased cost burden – or other barriers to care such as costly, time-consuming, or difficult to understand insurance hurdles. The administrative burden of these changes will be substantial for many people on modulators, and the additional costs after all options are exhausted will be prohibitively expensive for hundreds. We fear that both factors will result in patients having to stop or reduce their dose of modulator therapy; neither scenario is acceptable.

Another group that we are greatly concerned about is the pediatric CF population and those adults with mild lung disease. We are already receiving feedback that some of these patients may opt to permanently stop their modulators given the added cost burden until they sense a more pressing need for therapy. This will undo the education we have been providing to the CF community (and insurers) of the

[1] Trimble AT, Donaldson SH. Ivacaftor withdrawal syndrome in cystic fibrosis patients with the G551D mutation. J Cyst Fibros. 2018 Mar;17(2): e13-e16. doi: 10.1016/j.jcf.2017.09.006. Epub 2017 Oct 24. PMID: 29079142.

importance of early preventive therapy with highly effective CFTR modulators as well as putting patients at unneeded risk for irreversible loss of pulmonary function.

Because of the planned changes, our care center staff members are already devoting hours each day to answering calls and emails from the small group of patients who have started to address this issue, with the vast majority still unaware of this unfortunate program change. To support the CF Care Center Network and the anticipated additional administrative burden on them, the CF Foundation hosted a webinar on 10/20/2022 with presentations by expert CF pharmacy teams from around the country. Unfortunately, even among those well-versed on the subject, the primary sentiment was frustration and misunderstanding, as the impact of these changes remains elusive. In the aftermath of the pandemic with burnout at its highest, our care center teams are already stretched to the breaking point without having to devote countless hours to address this needless crisis. This unnecessary diversion of time and energy compromises the wellbeing of the CF patient community as well as those who care for them.

We, the undersigned, urge Vertex to rescind the 2023 program changes. If not permanently, then for one year to properly prepare and educate patients and care teams on the transition.

If you proceed with these high-risk changes, we ask that you expeditiously revise your process to ensure patients facing affordability concerns have uninterrupted access to their medications while navigating all necessary steps to afford their treatments.

I**f you choose to move forward with the changes, then we urge you to postpone implementation for one year to properly prepare and educate patients and care teams on the transition.** People with CF must have time to fully explore all available options to obtain affordable drugs without experiencing gaps in treatment.

By implementing these recommendations, Vertex will signal that they have the CF community's interests at heart by ensuring that all people with CF are able to access these transformative medications.

After such tremendous strides forward for so many fortunate enough to benefit from CFTR modulator therapies, the potential for deterioration in health status is untenable. At a time when the prevalence of anxiety and depression are at an all-time high, we are greatly concerned about the impact of these program changes on people with CF. For some it could be a matter of life and death. Others will have compromised clinical benefit due to forced trade-offs in other aspects of their care to make ends meet. On behalf of CF Program Directors around the country, we urge you to reconsider your position and revise the program. No person with CF should endure interruption in transformative modulator therapy or even the fear of that possibility. We look forward to your response.

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