Cystic Fibrosis Canada | FURTHER

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To: Canada's Life and Health Insurers

December 8, 2021

I am writing to you regarding coverage of a life-changing therapy for cystic fibrosis: Trikafta, the single biggest innovation in the history of the disease. Treating the basic defect of cystic fibrosis (CF), Trikafta is not only slowing the progression of the disease, it is transforming lives – getting them off transplant lists and helping them live longer, healthier lives – lives many of them never dreamed they would have.

Given the transformational nature of this drug, it was granted priority review by Health Canada and approved in 180 days by Health Canada for those who have cystic fibrosis who are 12 years of age or older with at least one copy of the F508del mutation. Health Canada's approval was issued on June 18, 2021. Thanks to an aligned review process, the drug received positive health technology assessment recommendations by CADTH and INESSS during this same timeframe.

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It is therefore puzzling and concerning that Canada's life and health insurers are not embracing this opportunity to change the course of a fatal disease. At this time, there are few insurers providing coverage for their clients who pay premiums so that they may access the medicines they need when they need them. Right now, the lack of private coverage is not only leaving people who solely rely on private coverage behind, but also causing issues and delays for people who have private insurance that will not cover Trikafta, who are trying to access the drug through the public system.

Your company has programs in place to help manage access to high value therapies across group and individual plans. Group benefit plans are using third party health technology assessment bodies like CADTH increasingly to determine access to life-saving medicines, rather than the services that your company provides.

It is therefore unacceptable that these third-party services are standing in the way of the access people rightfully need and deserve, through the plans you provide. These parties are increasingly turning to non-binding CADTH recommendations to deny access, recommendations that even our public payers have not adopted fully or found ways to accommodate coverage.

With all of this in mind, Cystic Fibrosis Canada calls on you to:

- Immediately fund Trikafta for all who could benefit from it.
- Encourage any group benefits plans insured through your company to use tools and industry-based evidence designed for the private insurance sector, not that which is developed for public insurers.
- Where there are delays in obtaining individual coverage, provide timely notice of denial so people can access public coverage while they wait for private coverage to kick in.

To assist in expediting your decision-making to list this drug, I have included:

We implore you to make changes so that Canadians living with cystic fibrosis can have the access to this life-changing drug. If you have any questions please contact Kim Steele, Director, Government and Community Relations at ksteele@cysticfibrosis.ca or by phone at 647-677-7704. We look forward to hearing from you early in the new year.

Regards,

Kelly Grover
President & CEO