Subject: Please Protect Patients with Cystic Fibrosis During COVID-19 Crisis: Early Refill of Prescription Medications

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Dear Mary Convento,

On behalf of Cystic Fibrosis Research, Incorporated (CFRI), and CFRI's key cystic fibrosis organizational partners, I write to urge you to protect patients during the COVID-19 crisis by issuing an emergency regulation requiring that insurers operating within your state permit a one-time early refill of covered prescription medications (including specialty medications), allow for extended refills, and lift barriers to obtaining medication from out-of-network



pharmacies. We also urge you to prepare for the possibility of supply chain disruptions by requiring insurers to cover off-formulary prescription drugs if there is no formulary drug available to treat the insured.

The CDC is currently advising people at high risk of complications – a group including people with disabilities, seniors, and those with chronic illnesses – to obtain and keep on hand a supply of prescription medications in the event that staying at home for prolonged periods of time becomes necessary. In practice, this is infeasible for most, since payers rarely cover refills until 3 to 7 days before a prescription is expected to run out.

Cystic fibrosis (CF) is a chronic, progressive, fatal, genetic disease for which there is no cure. Individuals with cystic fibrosis face a complex daily medical regimen, which often includes a combination of oral, inhaled, injected and IV medications. Many of these are considered specialty medications. Because those with cystic fibrosis are most likely to die from respiratory failure caused by progressive lung disease, the COVID-19 pandemic has very frightening consequences for our community. Sheltering in place with sufficient medications is vital.

Unfortunately, many people with CF, along with millions of others at high risk of complications, are not able to refill prescriptions early, nor have more than a 30-day supply. If this issue is not addressed, many of the state's residents at greatest risk of critical illness or death from COVID-19 will be forced to choose between traveling to pharmacies despite an active outbreak or abruptly discontinuing maintenance medication.

In the event that drug shortages or shipment disruptions occur during an outbreak, some patients may be unable to obtain medication at all.

Recognizing the urgency of the situation, on March 5th the Washington State insurance commissioner issued an emergency order requiring insurers to cover a one-time early refill of prescription medications.² On March 10th, the Center for Medicare and Medicaid Services issued guidance to Medicare Part D plans reminding them of their ability to relax restrictions on early refills and lift barriers to obtaining prescriptions from out-of-network pharmacies.³ New York State recently directed insurers to provide insurance coverage for off-formulary prescription drugs if there is not a formulary drug available to treat the insured.⁴ All of these are measures we should incorporate into your state's response to COVID-19.

Medication disruption endangers people's lives, both in and of itself and because the resulting destabilization of chronic conditions may worsen outcomes of acute illnesses like COVID-19. It also increases the risk of acute health crises requiring hospitalization at a time when healthcare systems are already at serious risk of exceeding capacity.

Some insurers have already chosen to allow early refills on their own initiative.⁵ We urge you to act to ensure all of the state's residents covered by public or private insurance can obtain a sufficient supply of prescription medication, including specialty drugs, to protect their health during this crisis.

As has been demonstrated elsewhere, once active community transmission begins, the crisis develops rapidly. We ask you to treat this as a public health emergency. To protect vulnerable residents of your state, we urge you to act with the utmost urgency to require insurers to cover early refills and remove barriers to filling them.

We thank you for your prompt attention to this matter. Should you have questions, please contact me, or any of the organizations' representatives listed below. Collectively, we serve cystic fibrosis patients and caregivers in every state. We are happy to serve as a resource to you at this challenging time.

Sincerely,

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¹ Centers for Disease Control and Prevention. (2020, March 8). People at risk for serious illness from COVID-19. Retrieved from: https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html.

²State of Washington, Office of Insurance Commissioner. (2020, March 5). Emergency Order No. 20-01. Retrieved from https://www.insurance.wa.gov/sites/default/files/documents/emergency-order-number-20-01.pdf.

³ Centers for Medicare & Medicaid Services. (2020, March 10). Information Related to Coronavirus Disease 2019 - COVID-19. Retrieved from https://www.cms.gov/files/document/hpms-memo-covid-information-plans.pdf.

⁴ Office of Governor Andrew M. Cuomo. (2020, March 2). Governor Cuomo announces new directive requiring New York insurers waive cost-sharing for coronavirus testing. Retrieved from https://www.governor.ny.gov/news/governor-cuomo-announces-new-directive-requiring-new-york-insurers-waive-cost-sharing.

⁵ Neighmond, P. (2020, March 9). How to boost your emergency supply of prescription medicines. National Public Radio. Retrieved from https://www.npr.org/sections/health-shots/2020/03/09/813704598/how-to-boost-your-emergency-supply-of-prescription-medicines.

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Cystic Fibrosis Research Inc. http://www.cfri.org/		

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Girl with Nebulizer PFDD

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