

May 8, 2020

The Honorable Michael Bennet United States Senate 261 Russell Senate Office Building Washington, D.C. 20150

Dear Senator Bennet,

On behalf of the Cystic Fibrosis Foundation, I write to provide comments on your draft legislation titled the *PASTEUR Act*. Thank you for this opportunity to provide input on this important work.

Cystic fibrosis is a rare genetic disease that affects over 30,000 people in the United States, including over 650 people in Colorado. The buildup of thick, sticky mucus in the lungs makes people with cystic fibrosis more prone to both acute and chronic bacterial infections. Routine use of antibiotics in CF care is medically necessary but unfortunately, too many people with CF find themselves battling difficult-to-treat infections where existing antibiotics are not effective.

We offer the following feedback on the establishment of the committee and on the creation of a list of microbes to target for new treatment development in the draft legislation.

Sec. 2. Establishment of Committee and Subscription Model

Certain patient populations – such as those with cystic fibrosis – are uniquely affected by infections and may have different treatment needs than the general population. For example, nontuberculous mycobacteria (NTM) is a dangerous pathogen that is increasingly impacting vulnerable populations like those in the CF community. Treatment typically requires at least 12 months of antibiotics, which can result in severe side effects that impact a patient's quality of life.

NTM, however, is not included in the Center for Disease Control and Prevention's (CDC) Antibiotic Resistance Threats in the United States Report. Other dangerous bacteria becoming more prevalent in the CF patient population, such as *Burkholderia cepacia*, are also not included on CDC's list. It is important that the committee not be limited to the antibiotic resistance threats list created by the CDC and that treatments meeting unique, and often smaller, population needs are able to qualify for a subscription contract under this model.

Additionally, we believe it will be beneficial to have experts with industry experience included in the committee in addition to physicians and academic experts. Experts across these areas are necessary to ensure that diverse perspectives on antibiotic development and use challenges are represented in the discussion. It is important that the committee set characteristics and standards for antimicrobials that are realistic, while reflecting unique patient population needs.

Thank you again for this opportunity to provide input on the *PASTEUR Act*. The CF Foundation is dedicated to reducing the impact of harmful bacteria on the CF community, and we appreciate this

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opportunity to share our community's needs. We look forward to working with you further on this effort.

Sincerely,

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Cystic Fibrosis Foundation