



June 18, 2019

The Honorable Kathy Castor
US House of Representatives
2052 Rayburn House Office Building
Washington, DC 20515

Dear Congresswoman Castor,

On behalf of the Cystic Fibrosis Foundation, I would like to express our support for designating a national week of awareness for nontuberculous mycobacteria (NTM). Establishing an NTM week of awareness will help improve public knowledge of this dangerous pathogen, which is increasingly impacting vulnerable populations like those in the CF community.

Cystic fibrosis is a rare genetic disease that affects over 30,000 people in the United States. The buildup of thick, sticky mucus in the lungs characteristic of the disease makes people with cystic fibrosis more prone to bacterial infections. Many people with CF suffer from difficult-to-treat acute or chronic infections, which can become life-threatening if not addressed adequately.

NTM infection is a growing concern in the CF community as more of the population becomes colonized with the pathogen. In 2017, approximately 13 percent of CF patients who had a culture performed were found to have NTM.¹ However, little is known about how NTM colonization impacts health, and treatment options are lacking. Treatment typically requires at least 12 months of antibiotics, which can result in severe side effects that impact a patient's quality of life. Public awareness of NTM and the challenges NTM lung disease presents is relatively low.

The Cystic Fibrosis Foundation is actively engaged in the research and development of new therapies for cystic fibrosis, including treatments to address pathogens that commonly infect patients with CF. The Foundation recently committed \$100 million over five years for our Infection Research Initiative. This new initiative supports a number of research projects aimed at improving detection, diagnosis, prevention, and treatment of infections related to cystic fibrosis including NTM. As part of our initiative, CFF recently awarded up to \$5.1 million specifically for NTM drug discovery and development.

The Foundation is committed to advancing care and treatment options for people with CF. However, we alone cannot address the unmet needs in the area of NTM research. Increasing the visibility of the patients who suffer from NTM lung disease and the challenges of treatment will be vital for spurring new opportunities for NTM research and therapeutic development.

We hope that you will consider supporting the establishment of an NTM national week of awareness. The CF Foundation is dedicated to reducing the impact of harmful bacteria on the

¹ <https://www.cff.org/Research/Researcher-Resources/Patient-Registry/2017-Patient-Registry-Annual-Data-Report.pdf> ©Cystic Fibrosis Foundation

CF community, and we appreciate this opportunity to share our community's needs and our infection research efforts. Please let us know if we can be of any further assistance on this endeavor.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight", written in a cursive style.

Mary B. Dwight
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation