

January 27, 2025

Representative Jonathan Warey, Chair  
House Committee on Industry, Business and Labor  
600 East Boulevard Avenue  
Room 327 C  
Bismarck, ND 58505

Dear Chairman Warrey and members of the Committee,

I am writing to you on behalf of the Cystic Fibrosis Association of North Dakota to express our strong support for **HB 1216**. This critical piece of legislation seeks to end the harmful practice of co-pay accumulators, which directly impacts the ability of individuals living with cystic fibrosis (CF) to afford life-saving medications.

The Cystic Fibrosis Association of North Dakota is dedicated to improving the lives of individuals living with cystic fibrosis, a rare and chronic genetic disease that affects the lungs, digestive system, and other organs. With no known cure, CF requires individuals to undergo frequent treatments, including daily medications, physical therapy, and sometimes hospitalizations. These treatments are vital to maintaining health and preventing life-threatening complications.

For people living with cystic fibrosis, access to medications is not just a matter of comfort—it is a matter of survival. However, co-pay accumulators are a growing barrier that many patients are facing. These programs prevent the financial assistance provided by pharmaceutical manufacturers from counting toward the patient's deductible and out-of-pocket maximum. As a result, patients are forced to pay out-of-pocket for medications that are extremely costly and with no generic equivalent.

For individuals with cystic fibrosis, who require specialized and high-cost medications, the financial burden caused by co-pay accumulators is overwhelming and devastating. Many families struggle to make ends meet and are left choosing between paying for necessary medications and basic necessities like housing or food. The consequences of not being able to afford these medications can be catastrophic, leading to deteriorating health, increased hospitalizations, and a significantly lower quality of life.

**HB 1216** is a critical step in protecting the health and well-being of North Dakota residents with cystic fibrosis and other chronic conditions by ensuring that the financial assistance provided through manufacturer programs is properly applied to the patient's out-of-pocket costs. This legislation will ensure that patients are not penalized for accessing financial assistance programs and will help alleviate the financial burden that many CF families are currently facing.

On behalf of the Cystic Fibrosis Association of North Dakota, I urge you to support **HB 1216** and help ensure that North Dakotans living with cystic fibrosis have access to the medications they need to live healthier, longer lives.

Thank you for your time and consideration.

Sincerely,  
Pam Thompson  
Development Director  
Cystic Fibrosis Association of North Dakota