



May 6, 2021

Assemblyman Kevin A. Cahill  
Chair, Standing Committee on Insurance  
New York State Assembly  
Legislative Office Building 714  
Albany, NY 12248

Dear Chairman Cahill and Members of the Assembly Insurance Committee,

On behalf of the approximately 1,600 people living with cystic fibrosis (CF) in New York, we are writing to express our support for SB 1413. As the cost of prescription insulin has risen drastically over the past decade, so too have patients' out-of-pocket costs, which threaten access to care for those who depend on the medication. SB 1413, which would limit insulin copayments to \$30 per 30-day supply, will help ensure patients, including those with cystic fibrosis-related diabetes (CFRD), are able to afford this vital treatment.

**We urge you to vote “yes” on SB 1413 to help ensure access to prescription insulin for people with CF.**

Cystic fibrosis is a life-threatening genetic disease that causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to serious infections. CF affects the whole body and requires an intensive daily treatment regimen to address its many manifestations. Eighty-four percent of CF patients also have at least one health complication in addition to cystic fibrosis including CFRD, asthma, sinus disease, and others.

Cystic fibrosis-related diabetes is one of the most common complications experienced by people with CF, occurring in five percent of adolescents and nearly one in three adults living with CF. Due to the progressive nature of the disease, CF can cause scarring or “fibrosis” of the pancreas, which can lead to insulin deficiency and CFRD. As the name suggests, cystic fibrosis-related diabetes is unique to people with CF and, therefore, manifests and is treated differently than other forms of diabetes. However, like type-1 and type-2 diabetes, insulin is a crucial part of the treatment regimen – according to the 2019 Cystic Fibrosis Patient Registry, nearly three-quarters of CFRD patients require chronic insulin use, often several times per day.<sup>1</sup>

Unfortunately, due to the high cost of insulin and other prescription drugs, many people with CF—even with the help of financial assistance—are forced to make difficult spending tradeoffs that can impact their health. According to a recent survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half of those surveyed reported delaying or forgoing care—including skipping medication doses, taking less medicine than prescribed, filling a prescription, or skipping a treatment altogether—due to cost concerns. Those living with CFRD who do not have consistent access to insulin may be unable to properly manage their blood sugar levels, putting them at increased risk of irreversible damage, costly hospitalizations, and declining health outcomes.

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<sup>1</sup> <https://www.cff.org/Research/Researcher-Resources/Patient-Registry/2019-Patient-Registry-Annual-Data-Report.pdf>

The cost of insulin also places additional financial strain on patients who may already be struggling to afford their care. In the aforementioned survey, people with CF report having the most difficulty paying for prescription drugs compared to any other component of their health care. Further, more than 70 percent of people with CF said paying for health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. Limiting copayments for insulin will help mitigate some of the financial burden that accompanies managing cystic fibrosis and CFRD.

**We urge you to vote “yes” on SB 1413 to help ensure access to prescription insulin for people living with CF.** As New York works to address the ongoing COVID-19 pandemic, it is more important than ever to ensure all patients have access to necessary medications, including insulin. The Cystic Fibrosis Foundation appreciates your attention to this important issue.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight", enclosed in a thin black rectangular border.

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