



April 13, 2023

Senator Susan Talamantes Eggman  
Chair, Senate Health Committee  
1021 O Street, Room 3310  
Sacramento, California 95814

Dear Chairwoman Eggman and Members of the California Senate Health Committee:

On behalf of the approximately 2500 people living with cystic fibrosis (CF) in California, we are writing to express our support for SB 90. 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 90 would limit insulin copayments to \$35 per 30-day supply. We urge you to vote "yes" on SB 90 to help ensure access to this vital treatment for people with cystic fibrosis-related diabetes (CFRD).

#### **Cystic fibrosis and CF-related diabetes**

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 in the lungs and pancreatic insufficiency. CF requires an intensive daily treatment regimen to address its many manifestations and eighty-six percent of CF patients also have at least one health complication in addition to cystic fibrosis, including cystic fibrosis-related diabetes (CFRD), asthma, sinus disease, and others.<sup>1</sup>

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.<sup>2</sup> Due to the disease's progressive nature, CF can cause scarring or "fibrosis" of the pancreas, which can lead to insulin deficiency and CFRD. Like type-1 and type-2 diabetes, treatment for CFRD relies on insulin.

#### **Access issues associated with CFRD**

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.<sup>3</sup> 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.

The cost of insulin places additional financial strain on patients who may already struggle to afford their care. In the aforementioned survey, people with CF reported having the most difficulty paying for

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<sup>1</sup> <https://www.cff.org/sites/default/files/2021-11/Patient-Registry-Annual-Data-Report.pdf>

<sup>2</sup> <https://www.cff.org/sites/default/files/2021-11/Patient-Registry-Annual-Data-Report.pdf>

<sup>3</sup> [https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs\\_policy\\_briefs](https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs)

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 90 to help ensure access to prescription insulin for people living with CF.** Thank you for 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