



May 22, 2023

The Honorable Susan Collins
United States Senate
413 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Jeanne Shaheen
United States Senate
506 Hart Senate Office Building
Washington, DC 20510

Dear Senator Collins and Senator Shaheen:

On behalf of the Cystic Fibrosis Foundation, we are pleased to endorse the *Improving Needed Safeguards for Users of Lifesaving Insulin Now (INSULIN) Act of 2023*. This bipartisan legislation, which will take steps to lower the price of insulin, reduce out-of-pocket costs for patients in group and individual market health plans, limit formulary management barriers like prior authorization, and promote access to generic and biosimilar options, will help ensure patients, including those with cystic fibrosis-related diabetes (CFRD), are able to afford this vital treatment.

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-six 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 2021 Cystic Fibrosis Patient Registry, nearly three-quarters of CFRD patients require chronic insulin use, often several times per day.¹

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.

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

The cost of insulin 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. Limiting copayments for insulin will help mitigate some of the financial burden that accompany managing cystic fibrosis and CFRD.

Thank you for your leadership on this critical issue. We appreciate your hard work to ensure insulin out-of-pocket caps for Medicare beneficiaries were included in the Inflation Reduction Act.² The CF Foundation stands ready to work with you and the members of the Diabetes Caucus to help pass this important bipartisan legislation to ensure patients in the commercial market have access to more affordable insulin. If we can be of any further assistance, please contact David Elin, Senior Director of Policy & Advocacy, at delin@cff.org.

Sincerely,



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

² <https://www.cff.org/sites/default/files/2022-08/CF-Foundation-Letter-Inflation-Reduction-Act.pdf>