

April 15, 2022

The Honorable Jeanne Shaheen
Senate Diabetes Caucus Co-Chair
United States Senate
506 Hart Senate Office Building
Washington, D.C. 20510

The Honorable Susan Collins
Senate Diabetes Caucus Co-Chair
United States Senate
413 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Diana DeGette
House Diabetes Caucus Co-Chair
United States House of Representatives
2111 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Tom Reed
House Diabetes Caucus Co-Chair
United States House of Representatives
1203 Longworth House Office Building
Washington, D.C. 20515

RE: Comments Regarding Policy Priorities to Ensure Access to Insulin and Stop Insulin Price Gouging

Dear Sens. Shaheen and Collins and Reps. DeGette and Reed:

Public Citizen, a consumer advocacy organization with more than 500,000 members and supporters nationwide, respectfully submits the following comments regarding policies to ensure access to insulin and stop insulin price gouging. We are grateful for your efforts to improve affordable access to insulin for people living with diabetes and appreciate the opportunity to provide stakeholder feedback. As you proceed with refining this proposal, it is essential to prioritize expanding access to affordable insulin to people without insurance and to ensure insulin manufacturing corporations face penalties should they choose to continue price gouging patients.

More than 30 million people in the United States live with diabetes, an estimated one-third of whom use insulin to manage the condition.^{1,2} For many people with diabetes, access to insulin is a matter of life and death.³

Insulin patients with inadequate or no insurance confront high prices directly through exorbitant out-of-pocket costs. Nearly one-in-four patients who use insulin report rationing treatment.⁴ This rationing can lead to irreversible health outcomes, including blindness and death.

¹ <https://www.cdc.gov/diabetes/library/spotlights/diabetes-facts-stats.html>

² <https://www.commonwealthfund.org/publications/issue-briefs/2020/sep/not-so-sweet-insulin-affordability-over-time>

³ <https://www.t1international.com/type-1-diabetes/>

⁴ Public Citizen, T1International, Legislative Guide for Insulin for All (2020), <https://www.citizen.org/article/legislative-guide-for-insulin-for-all/>

This letter will highlight two top priorities for strengthening your insulin legislation before moving forward:

1) Ensuring that people without insurance have affordable access to insulin

Your proposed out-of-pocket cap would ensure that patients with insurance face no more than \$35 in monthly out-of-pocket costs for at least one type of insulin in each category. This would be a lifeline to patients with weak insurance, and that alone is a reason to proceed with an out-of-pocket cap. However, this cap only would help around 20-30% of insured insulin patients, and it would do nothing to improve affordability and access for the uninsured.⁵

Recommendation:

Expand out-of-pocket protections to include people without insurance. One approach is through similar modalities to those used during the pandemic to provide people without insurance access to vaccines, testing and treatment. Rep. Doggett has offered amendment language for the *Affordable Insulin Now Act* to that effect.

2) Strengthen measures to lower insulin prices through penalties against ongoing price gouging

Your proposal seeks to encourage drug corporations to lower insulin prices to 2006 levels. This could mean substantial price reductions, which in turn would provide relief to patients without insurance, as well as prevent out-of-pocket caps from leading to increased burdens on patients through higher premiums. But that is contingent on the efficacy of the proposed incentive to lower prices, which is questionable, at best.

To entice drug corporations to lower prices, your proposal would require insurers to cover such insulins with no more than \$35 in monthly out-of-pocket costs. However, as noted above, capping \$35 in monthly out-of-pocket costs would benefit a relatively small proportion of people with insurance who use insulin. Consequently, the requirement may represent an ineffective ‘carrot’ to spur price reductions. Absent further mechanisms, some or all insulin manufacturers may choose to continue with the high-price, high-rebate model which leads to price gouging and preventable suffering and death of people who depend on insulin.

Recommendation:

Incorporate penalties against insulin manufacturers that do not lower prices, instead of relying only on voluntary participation as under your current proposal.⁶ Your legislation will be dramatically strengthened by incorporating a penalty requiring manufacturers to pay a rebate to

⁵ <https://www.healthsystemtracker.org/brief/out-of-pocket-spending-on-insulin-among-people-with-private-insurance/>

⁶ Insulin price spiking began long before the year 2006, so an earlier benchmark period would be appropriate and provide deeper price reductions. See: <https://www.washingtonpost.com/news/wonk/wp/2016/10/31/why-insulin-prices-have-kept-rising-for-95-years/>

the U.S. government when the Wholesale Acquisition Cost (WAC) of an insulin product is higher than its 2006 level (or earlier, preferably). A well-designed excise tax approach would provide a powerful ‘stick’ as well.

Conclusion

Legislation supporting access to insulin should: (1) account for the needs of the most vulnerable and (2) hold manufacturers accountable for price abuse. The above proposed amendments would help save lives while reducing prices. We invite your offices to contact us with any questions.

Insulin is egregiously expensive, yet diabetes is hardly the only condition for which Americans cannot afford prescriptions. We look forward to working with you to improve access to all life-saving medications.

Sincerely,

A handwritten signature in black ink, reading "Peter Maybarduk". The signature is fluid and cursive, with the first name "Peter" being larger and more prominent than the last name "Maybarduk".

Peter Maybarduk
Director, Access to Medicines Program
Public Citizen