



April 19, 2022

The Honorable Jeanne Shaheen
United States Senate
Washington, DC 20510

The Honorable Susan Collins
United States Senate
Washington, DC 20510

The Honorable Diana DeGette
U.S House of Representatives
Washington, DC 20515

The Honorable Tom Reed
U.S. House of Representatives
Washington, DC 20515

Dear Senators Shaheen and Collins and Representatives DeGette and Reed:

Thank you for the opportunity to provide feedback on your legislative framework to address the cost of insulin, an issue critical for so many individuals and families across our country. Families USA appreciates your efforts to address this issue, recognizing that every day in America people are forced to make the financial decision between paying for their life-sustaining medication or other basic needs such as food. We agree that legislative action is necessary to address this crisis and your proposed framework has the potential to help many of the more than 30 million Americans who live with diabetes. However, as you know, this proposal alone simply cannot do enough to help every family that has to deal with the egregious price gouging of insulin, nor will it address our broader drug pricing crisis. After decades of unjustifiable price increases on a broad array of lifesaving medications, it is time to solve the problem and take bold and decisive action to reduce the burden of prescription drug costs for all American families.

Your proposal to cap the cost of insulin and make insulin eligible for coinsurance will go a long way to relieve some of the financial burden for millions of families that need it. However, by relying on incentives for industry to lower costs without authoritatively addressing list price, we have concerns that families will encounter increased costs in other aspects of the health care system. Cost shifting is rampant in our health care system, and without directly tackling root causes of high drug prices, any savings at the point of sale for families will be paid in rising costs in the health care system such as premiums or deductibles, which are already unaffordable for too many. In fact, premiums have increased at a faster rate than wages, and high deductibles have contributed to 41% of underinsured Americans forgoing care due to the cost.ⁱ We appreciate recognition that pharmacy benefit manager rebates are one of many causes for rising costs, but only addressing the rebates will not go far enough to truly bring accountability to lower the list price. Time and time again we have seen efforts by pharmaceutical companies to take advantage of loopholes and incentives and firmly believe the best tool to bring down list price is through price negotiation.

Further, we appreciate that the framework improves affordability for people enrolled in group and individual market health plans, but we are concerned that it would not do enough to help people who do not have health insurance. The American Rescue Plan Act helped more families than ever afford insurance, but 31 million people remained uninsured in the first six months of 2021.ⁱⁱ Uninsured people and those with a gap in coverage, who represent 17% of the insulin-using population with diabetes, constituted 80% of those who paid full price for an insulin prescription. Additionally, they are more likely

to use cheaper, older and sometimes less effective formulations of insulin.ⁱⁱⁱ Any policy to address health care costs must focus on those that have the most need, and it is clear that uninsured Americans feel the drug price crisis most acutely.

Finally, the prescription drug affordability crisis is unfortunately not unique to insulin, with one in four Americans having reported difficulty affording their prescriptions and three in ten saying they haven't taken their medication because of the high costs.^{iv} Overall, drug prices have increased much faster than most other household costs and much faster than our paychecks.^v It is critical that Congress takes steps to reduce the cost of insulin, but it should not leave behind the millions of people who also struggle to afford a myriad of life-saving and sustaining medications. Authorizing Medicare to negotiate for fair prices would reduce the cost of drugs for millions of people for much-needed medications, including insulin. This tool provides a comprehensive method for dealing with the high costs of drugs, rather than attempting to address each drug one at a time. The American people are very clear that this is the solution they need. In fact, 95% of voters overwhelmingly support giving Medicare the ability to negotiate for lower prices.^{vi}

Thank you again for your leadership and your commitment to working with your colleagues across the political aisle to put forward solutions that can provide immediate relief to families at a time when they need it most. We commend you for the work you have already done and we look forward to working together to build off of this critical foundation to enact meaningful and lasting drug pricing reforms. Please contact Bailey Reavis at breavis@familiesusa.org with any questions about our feedback or Families USA's policy priorities.

Sincerely,

Jen Taylor
Senior Director of Federal Relations

ⁱ <https://www.thirdway.org/report/cost-caps-and-coverage-for-all-how-to-make-health-care-universally-affordable>

ⁱⁱ <https://www.aha.org/news/headline/2021-11-17-cdc-reports-uninsured-first-six-months-2021>

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

^{iv} <https://www.consumerreports.org/drug-prices/how-to-pay-less-for-your-meds/>

^v Juliette Cubanski and Tricia Neuman, "Prices Increased Faster Than Inflation for Half of all Drugs Covered by Medicare in 2020" The Henry J. Kaiser Family Foundation, February 25, 2022

<https://www.kff.org/medicare/issuebrief/prices-increased-faster-than-inflation-for-half-of-all-drugs-covered-by-medicare-in-2020/>

^{vi} Sandra Wilkniss, Kimberly Alleyne, and Natasha Kumar, "Affordable Medicines are Still Elusive: America's Families Want Fair Prices." December 11, 2020. <https://www.familiesusa.org/resources/affordable-medicines-are-stillelusive-americas-families-want-fair-prices/>