

Congress of the United States
Washington, DC 20515

July 29, 2022

The Honorable Nancy Pelosi
Speaker of the House
U.S. House of Representatives
H-232, The Capitol
Washington, D.C. 20515

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
H-204, The Capitol
Washington, D.C. 20515

The Honorable Chuck Schumer
Majority Leader
United States Senate
S-221, The Capitol
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
United States Senate
S-230, The Capitol
Washington, DC 20510

Dear Speaker Pelosi, Minority Leader McCarthy, Majority Leader Schumer, and Minority Leader McConnell,

We write to express grave concern with the exclusion of uninsured people in the proposed legislation to establish a \$35 out-of-pocket cost caps on insulin and to urge you to include this population in these caps. Failure to do so will deepen health disparities and increase long-term healthcare costs. Moreover, we risk additional deaths from untreated and under-treated diabetes simply because of the outrageous price of insulin. Individuals with diabetes who require daily insulin injections risk dying if they lose access to insulin for even a few days.

The price of insulin has risen more than 1,000 percent since 1999, causing a dangerous affordability crisis in America.¹ There are 37.3 million Americans with diabetes, including nearly 2 million uninsured people with diabetes.^{2,3} In addition to those uninsured for extended periods of time, 1 out of 4 privately-insured Americans with diabetes experienced at least one gap in insurance for at least 30 days in the past three years.⁴ Whether without insurance for an extended period of time or for 30 days due to life events such as job transitions or marriage, uninsured people with diabetes often pay over \$1,000 per month for their insulin. Uninsured individuals are roughly

¹ [https://www.mayoclinicproceedings.org/article/S0025-6196\(19\)31008-0/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(19)31008-0/fulltext)

² <https://www.cdc.gov/diabetes/library/spotlights/diabetes-facts-stats.html#:~:text=37.3%20million%20Americans%E2%80%94about%201,t%20know%20they%20have%20it.>

³ <https://diabetesjournals.org/care/article/42/11/e179/36343/The-Affordable-Care-Act-and-Health-Insurance>

⁴ <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.0204>

twice as likely to report that they cannot afford their diabetes medications compared to those Americans with diabetes who have insurance.⁵

Sadly, there are many tragic accounts of uninsured people with diabetes who could not afford their insulin and died as a result of insulin rationing. One such tragic and preventable story is that of Alec Smith, a 26-year-old who died from insulin rationing just one month after aging out of his mother's insurance and becoming uninsured.⁶ It is clear that the sky-high price of insulin poses a direct threat to the lives of many Americans with diabetes.

Diabetes disproportionately affects people of color, with the risk of having a diabetes diagnosis 77 percent higher among Black Americans, 66 percent higher among Hispanic Americans, and 18 percent higher among Asian Americans compared to white Americans.⁷ Additionally, people of color with diabetes are significantly more likely to be uninsured. A 2021 study in the *Lancet* demonstrated that within the diabetes community, 2.2 percent of white people were uninsured compared to 6.4 percent of Black people, 32.6 percent of Hispanic people, and 15.3 percent of Native American and Alaskan Native people.⁸ Therefore, legislation that caps the out-of-pocket cost of insulin *only* for people with private insurance or Medicare will leave many racial and ethnic groups behind and create a new racial health disparity in our health system, which is already fraught with many other disparities.

Including uninsured people in proposed insulin out-of-pocket caps will also decrease long-term healthcare spending. People with diabetes who are uninsured are a major driver of emergency room and hospital usage. Patients with gaps in their health insurance in the past three years were five times more likely to end up in an emergency room or hospital while uninsured than while they were insured.⁹ Further, uninsured patients are at an increased risk for poor health outcomes from diabetes including kidney failure, cardiac disease, and blindness.^{10,11} These poor outcomes result from lack of access to care and insulin needed to control diabetes. Establishing a \$35 out-of-pocket cost cap for uninsured people with diabetes will decrease the rate of diabetes complications and correspondingly decrease future national health expenditures.

The \$35 cap on out-of-pocket insulin costs could be expanded to include the uninsured in a number of ways. We suggest one of the following:

⁵<https://www.commonwealthfund.org/publications/issue-briefs/2020/sep/not-so-sweet-insulin-affordability-over-time>

⁶<https://www.npr.org/sections/health-shots/2018/09/01/641615877/insulins-high-cost-leads-to-lethal-rationing>

⁷ <https://diabetesjournals.org/care/article/39/5/743/30624/Racial-and-Ethnic-Disparities-in-Diabetes-Care-and>

⁸ [https://www.thelancet.com/pdfs/journals/lanam/PIIS2667-193X\(21\)00107-1.pdf](https://www.thelancet.com/pdfs/journals/lanam/PIIS2667-193X(21)00107-1.pdf)

⁹ <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.0204>

¹⁰ <https://journals.sagepub.com/doi/10.1177/2150131913481807>

¹¹<https://diabetesjournals.org/care/article/35/7/1566/30411/Access-to-Health-Care-and-Control-of-ABCs-of>

1) The government use existing Medicaid payment structures to reimburse retail pharmacies for the difference between the list price and the \$35 payment from uninsured people who fill their insulin prescriptions; or

2) HHS creates a fund to reimburse health care providers and pharmacies for insulin disbursed to uninsured individuals, similar to the HRSA COVID-19 Uninsured Program.

We strongly support efforts to decrease the price of insulin and enable Americans with diabetes to afford their medication. We urge you to include the uninsured in the \$35 out-of-pocket cost caps to any legislation addressing insulin pricing that Congress considers. Inclusion of uninsured people in insulin pricing legislation will help prevent new racial health disparities resulting from this legislation, curb future deaths of Americans due to insulin rationing, and decrease the likelihood of diabetes complications.

Thank you for your consideration. We look forward to working with you on this critical issue and voting on legislation that will cap insulin prices for all people with diabetes, regardless of their insurance status. Thank you for your attention to this important matter.

Sincerely,



PRAMILA JAYAPAL
Chair
Congressional Progressive Caucus



JOYCE BEATTY
Chair
Congressional Black Caucus



RAUL RUIZ, M.D.
Chair
Congressional Hispanic Caucus



JUDY CHU
Chair
Congressional Asian Pacific American
Caucus

/s/

NANNETTE DIAZ BARRAGÁN

Member of Congress

/s/

ALMA S. ADAMS, Ph.D.

Member of Congress

/s/

COLIN ALLRED

Member of Congress

/s/

KAREN BASS

Member of Congress

/s/

SANFORD D. BISHOP, JR.

Member of Congress

/s/

EARL BLUMENAUER

Member of Congress

/s/

JAMAAL BOWMAN, Ed.D.

Member of Congress

/s/

ANTHONY G. BROWN, M.D.

Member of Congress

/s/

JULIA BROWNLEY

Member of Congress

/s/

CORI BUSH

Member of Congress

/s/

SALUD CARBAJAL

Member of Congress

/s/

TONY CÁRDENAS

Member of Congress

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JOAQUIN CASTRO

Member of Congress

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DAVID CICILLINE

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GERALD E. CONNOLLY

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DANNY K. DAVIS
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KAI KAHELE
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MADELEINE DEAN
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MARK DESAULNIER
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RAÚL M. GRIJALVA
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STEVEN HORSFORD
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SARA JACOBS
Member of Congress

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EDDIE BERNICE JOHNSON
Member of Congress

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HENRY C. "HANK" JOHNSON, JR.
Member of Congress

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MONDAIRE JONES
Member of Congress

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WILLIAM R. KEATING

Member of Congress

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DONALD M. PAYNE, JR.

Member of Congress

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BARBARA LEE

Member of Congress

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ANDY LEVIN

Member of Congress

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TED W. LIEU

Member of Congress

/s/

ALAN LOWENTHAL

Member of Congress

/s/

CAROLYN B. MALONEY

Member of Congress

/s/

JIM MCGOVERN

Member of Congress

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GERALD MCNERNY

Member of Congress

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GRACE MENG

Member of Congress

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GWEN MOORE

Member of Congress

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JERROLD NADLER

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GRACE F. NAPOLITANO

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MARIE NEWMAN

Member of Congress

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ELEANOR HOLMES NORTON

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ILHAN OMAR

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CHELLIE PINGREE
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MARK POCAN
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AYANNA PRESSLEY
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AL GREEN
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TERRI A. SEWELL
Member of Congress

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HALEY STEVENS
Member of Congress

/s/

MIKE THOMPSON
Member of Congress

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NYDIA M. VELÁZQUEZ
Member of Congress

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KATIE PORTER
Member of Congress

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JAMIE RASKIN
Member of Congress

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JAN SCHAKOWSKY
Member of Congress

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RAÛL M. GRIJALVA
Member of Congress

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ADAM SMITH
Member of Congress

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MARK TAKANO
Member of Congress

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RITCHIE TORRES
Member of Congress

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BONNIE WATSON COLEMAN
Member of Congress

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PETER WELCH
Member of Congress

/s/

NIKEMA WILLIAMS
Member of Congress

/s/

CHRIS PAPAS
Member of Congress

/s/

RASHIDA TLAIB
Member of Congress

/s/

JESUS G. "CHUY" GARCIA
Member of Congress

/s/

ANGIE CRAIG
Member of Congress

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MIKE THOMPSON
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NYDIA M. VELÁZQUEZ
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SUSAN WILD
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