December 7, 2021

The Honorable Chuck Schumer
Majority Leader
United States Senate
322 Hart Senate Office Building
Washington, D.C. 20510

Dear Majority Leader Schumer,

Thank you for your leadership in the Senate throughout the negotiations on the Build Back Better Act. We appreciate your work with us to include bold healthcare expansions in this bill. We write to emphasize the importance of retaining the current out-of-pocket payment cap for insulin at $35 per month and to request that you implement these payment caps earlier and expand them to uninsured people in the final bill.

The need for interventions to lower the cost of insulin has never been greater. The list price for the most effective insulins has risen over 1,000 percent since 1999.1 Due to these skyrocketing prices and other high health insurance costs, one in four people with diabetes ration their insulin.2 When a person with diabetes is forced to ration insulin due to cost, they are aware of the risks, such as loss of sight and kidney function, or even death, but they are left with no choice but to put their health in jeopardy. Sadly, despite the existence of effective diabetes treatment protocols, many people with diabetes have died from rationing their insulin due to cost. Death from insulin rationing is caused by diabetic ketoacidosis (DKA) in which a person’s blood turns acidic and causes organ failure.3 Insulin rationing deaths are particularly cruel because nearly all people with diabetes know the risk of DKA and what it can do to their body, but they have no ability to prevent it because large pharmaceutical companies hold their life-saving insulin hostage at unattainable prices.

The House-passed Build Back Better Act contains provisions which cap the cost for a patient’s monthly insulin prescription at $35 for all Medicare beneficiaries and privately insured people. Importantly, this cap applies regardless of if a patient has spent down their deductible or not. This provision will make insulin affordable for the 32 million insured adults with diabetes in the U.S.4,5 In the current bill, these caps take effect in 2023. We urge you to amend the bill to

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1 Rajkumar, S. The High Cost of Insulin in the United States: An Urgent Call to Action (Mayo Clinic Proceedings, 2020).
2 Herkert D, Vijayakumar P, Luo J. Cost Related Insulin Underuse Among Patients with Diabetes (JAMA Internal Medicine, 2019).
5 Myerson R, et al. The Affordable Care Act and Health Insurance Coverage Among People with Diagnosed and Undiagnosed Diabetes: Data from the National Health and Nutrition Survey (Diabetes Care, 2019).
implement the caps in 2022 to provide immediate relief for patients struggling with high insulin costs right now. The health security that this will offer to people with diabetes across the country will be transformational. Further, enabling better control of diabetes will decrease future healthcare costs for complications, such as dialysis for kidney failure which is funded by the U.S. government. We strongly urge you to fight to retain this crucial drug affordability benefit in the Senate Build Back Better Act.

As the Build Back Better Act advances in the Senate, we urge you to build on the House’s work and extend the $35 monthly insulin payment cap to uninsured people. This can be done through payment from the government for the difference between the $35 patient payment and the list price of the insulin by utilizing the existing infrastructure in Medicaid for reimbursement of retail pharmacies. Being uninsured, even for a short period during a job transition or marriage status change, can be deadly for a person with diabetes who will have to pay full retail price for their insulin during that time. Expansion of the payment cap to uninsured people would guarantee that every person with diabetes will only pay $35 for their monthly insulin. Further, it will ensure that no Americans die due to insulin rationing again.

We strongly urge you to retain the insulin affordability provisions in the House-passed Build Back Better Act, implement these provisions sooner, and expand these provisions to apply to the uninsured population. These provisions have the potential to immediately save lives and prevent complications of untreated diabetes for millions of Americans. While only federal list price caps will completely prevent pharmaceutical price gouging, the out-of-pocket payment caps in this bill will be a transformational first step to address the dangerously high drug prices plaguing Americans. By retaining and expanding the insulin cost caps, we can pass a bill that truly makes insulin affordable for everyone in the U.S. We look forward to continuing our partnership with the Senate to fight for the boldest healthcare provisions possible in the Build Back Better Act and to passing this bill into law to directly improve the lives of all Americans with diabetes.

Sincerely,

PRAMILA JAYAPAL
Member of Congress

/s/
ALMA S. ADAMS, Ph.D.
Member of Congress

/s/
COLIN ALLRED
Member of Congress

/s/
RICK LARSEN
Member of Congress

/s/
JOHN B. LARSON
Member of Congress
NANETTE DIAZ BARRAGÁN  
Member of Congress

BRENDA LAWRENCE  
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JULIA BROWNLEY  
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Member of Congress

ANDRÉ CARSON  
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JERROLD NADLER  
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GRACE F. NAPOLITANO  
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JOAQUIN CASTRO  
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JOE NEGUSE  
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/s/ RAÚL M. GRIJALVA
Member of Congress

/s/ JOSH HARDER
Member of Congress

/s/ SHEILA JACKSON LEE
Member of Congress

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

/s/ MONDAIRE JONES
Member of Congress

/s/ RO KHANNA
Member of Congress

/s/ ANN KIRKPATRICK
Member of Congress

/s/ DANIEL T. KILDEE
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/s/ VERONICA ESCOBAR
Member of Congress

/s/ TERESA LEGER FERNÁNDEZ
Member of Congress

/s/ MAXINE WATERS
Member of Congress

/s/ NYDIA M. VELÁZQUEZ
Member of Congress

/s/ BONNIE WATSON COLEMAN
Member of Congress

/s/ PETER WELCH
Member of Congress

/s/ SUSAN WILD
Member of Congress

/s/ NIKEMA WILLIAMS
Member of Congress

/s/ FREDERICA S. WILSON
Member of Congress

/s/ LISA BLUNT ROCHESTER
Member of Congress

/s/ DANNY K. DAVIS
Member of Congress