

The Honorable Chuck Schumer
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker
United States House of Representatives
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, DC 20510

The Honorable Kevin McCarthy
Minority Leader
United States House of Representatives
Washington, DC 20515

November 14, 2022

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

Today on World Diabetes Day, our organizations call on Congress to urgently pass legislation to ensure that people in the United States have affordable access to the insulin that they need to live. World Diabetes Day marks the birthday of Frederick Banting, who discovered insulin and famously sold its patent for \$1 and stated, “Insulin does not belong to me, it belongs to the world.”¹ Despite its discovery more than 100 years ago and the generosity of Banting and the co-inventors, many people living in the United States still struggle to afford access to the insulin they need.

We are grateful for the progress made recently through the passage of the Inflation Reduction Act that will limit Medicare Part D beneficiaries’ monthly out-of-pocket costs for each insulin prescription to \$35. And, this reform barely scratches the surface of what is needed to truly expand insulin access and likely does nothing to lower the excessive prices charged by insulin manufacturers.²

A recent study published in the Annals of Internal Medicines found that 1.3 million people in the United States ration insulin.³ Another recent survey showed as many as 1 in 4 people with type 1 diabetes ration insulin.⁴ People without insurance were most likely to ration insulin (29.2% ration insulin), followed by those with private insurance (18.8%).⁵ Rationing is disproportionately high for Black Americans, of whom 23.2% ration insulin, compared with 16% of Hispanic and White Americans.⁶

As people in the United States struggle to access affordable insulin, the big three drug corporations that manufacture insulin have repeatedly and sharply raised prices and aggressively sought to extend lucrative product monopolies, resulting in many billions of dollars in excessive spending.⁷

¹ <https://www.t1international.com/100years/>

² <https://www.citizen.org/article/prices-for-leading-insulins-will-likely-not-be-negotiated-under-new-drug-pricing-package/>

³ <https://www.acpjournals.org/doi/full/10.7326/M22-2477>

⁴ <https://www.sciencedirect.com/science/article/pii/S0168822721003557>

⁵ <https://www.acpjournals.org/doi/full/10.7326/M22-2477>

⁶ <https://www.acpjournals.org/doi/full/10.7326/M22-2477>

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<https://oversight.house.gov/sites/democrats.oversight.house.gov/files/DRUG%20PRICING%20REPORT%20WITH%20APPENDIX%20v3.pdf>

Any insulin reform legislation advanced by legislators must achieve two essential goals:

- 1) Ensure people without insurance and people with private insurance, who are most vulnerable to rationing, have access to the insulin they need.**

Alec Smith was 26 years old when he aged out of his parents' health insurance.⁸ He made just enough not to qualify for insurance subsidy or patient assistance programs, meaning, like many people without insurance, he was forced to face the full price for his insulin out of pocket. As a result, Alec rationed his insulin supply to wait to afford more, but within days, he died of ketoacidosis.

Any insulin legislation that would not have prevented this tragedy fails the Alec Smith test. It is vital that affordable insulin access is provided to everyone who does not have insurance, in addition to those who are privately insured.

- 2) Stop insulin manufacturers from charging excessive prices.**

Since the 1990's, insulin manufacturers have raised prices many times over for U.S. patients, as much as 1100%, despite their products remaining largely unchanged, and low production costs.⁹

Abusive pricing of insulin, which the very same corporations who sell insulin here sell for a fraction of the price in other wealthy countries,¹⁰ has led to immense profits for these corporations at the cost of preventable suffering and death of people who need insulin, in addition to billions of dollars drained from government coffers and consumers' bank accounts.

Any insulin legislation that fails to lower the prices charged by insulin manufacturers would fail to hold these corporations accountable, in effect rewarding them for decades of price gouging. Legislation reining in insulin prices should not take a carrot-only approach or rely on voluntary concessions from insulin manufacturers to do so.

Thank you again for your time and attention. We look forward to working with you to deliver meaningful reform that will ensure everyone, including people without insurance, have access to insulin and to lower unfair and excessive prices.

Sincerely,

ACA Consumer Advocacy

Community Catalyst

American Academy of Family Physicians

Congregation of Our Lady of Charity of the Good Shepherd, U.S. Provinces

American-Arab Anti-Discrimination Committee (ADC)

Covid-19 Longhailer Advocacy Project

Beta Cell Foundation

Dana Investment Advisors

Colorado Consumer Health Initiative (CCHI)

Doctors for America

⁸ <https://www.pbs.org/wgbh/blood-sugar-rising/home/portraits/the-smithholt-family/>

⁹ <https://www.nbcnews.com/business/consumer/desperate-families-driven-black-market-insulin-n730026>

¹⁰ https://www.rand.org/pubs/research_reports/RRA788-1.html

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Families USA
Family Voices
Fayetteville Police Accountability Community Taskforce
Florida Chapter #insulin4all
Generation Patient
Health Access California
Health Care Voices
Idaho #insulin4all
Indivisible
Interfaith Center on Corporate Responsibility
Just Care USA
Maryland Health Care for All! Coalition
Medicare Rights Center
Michigan #insulin4all Chapter
Minnesota Insulin 4 All
Mutual Aid Diabetes
National Advocacy Center of the Sisters of the Good Shepherd
National Association of Councils on Developmental Disabilities
National Council of Jewish Women
National Health Law Program
NC Justice Center
National Domestic Workers Alliance (NDWA)
Network Lobby for Catholic Social Justice
New York #insulin4all

North Carolina Medicare For All Coalition
Northwest Coalition for Responsible Investment
Ohio #insulin4all
Oregonizers
People's Action
Physicians for a National Health Program
Public Citizen
Right to Health Action
Seventh Generation Interfaith Coalition for Responsible Investment
Sisters of Charity of Saint Elizabeth
Sisters of St. Francis Dubuque
Social Security Works
T1International
The Diabetes Link @ Yale
The Insulin Initiative
United Church of Christ Justice and Local Church Ministries
Utah #insulin4all