

**Testimony at the New York State Legislature Joint Hearing on Health**  
**Honorable Senator Gustavo Rivera, Chair of the Senate Health Committee**  
**Honorable Assemblymember Richard Gottfried, Chair of the Assembly Health Committee**  
**New York #Insulin4All Testimony delivered by Karlynn Holland, Chapter Leader**  
**1/29/2020**

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I am testifying today on behalf of New York #insulin4all. We are an advocacy chapter of the not for profit organization T1international that works for insulin affordability in America, and across the world. All of our members are volunteer patient advocates fighting for our lives, because without affordable insulin, we die.

New York #insulin4all is testifying to ensure affordable insulin access is achieved in 2020 for all insulin-dependent New Yorkers across income, race, disability and insurance status.

We thank Governor Cuomo for his expressed support for the \$100/month co-pay cap. This is an important step, however the co-pay cap will only be applicable to approximately 27% of the NYS population who have private insurance through the marketplace<sup>1</sup>. This is not enough to protect my community. It is common sense to ensure insulin access for the approximately half-million insulin-dependent New Yorkers while saving New York State billions annually in hospitalization and long-term complication costs. We echo the words of Nobel Peace prize-nominated and leading community health advocate Chris Norwood of HealthPeople.org<sup>2</sup>: **“With diabetes properly addressed, there is NO medicaid budget crisis”**. Affordable insulin access is a key component of the solution.

**In New York State, 10.9%<sup>3</sup> of the population lives with diabetes<sup>4</sup>.** 2019 diabetes rates in NYS across ethnicities are<sup>5</sup>: 17.5% American Indian/Alaskan Native; 11% Hispanic; 14.5% non-Hispanic blacks; 15.1% non-Hispanic Asians; and 9.2% non-Hispanic whites.

**There are two basic types of diabetes:** Type 1 diabetes is a lifelong and incurable auto-immune condition that requires daily insulin injections for survival. **100% of people with Type 1 diabetes are insulin-dependent.** Around 5% of the total U.S. diabetes population is Type 1. Type 2 diabetes is a chronic metabolic condition that makes the body’s insulin less efficient. While not all people with Type 2 diabetes require insulin, **approximately 30% of people with Type 2 are insulin dependent.**

To determine the percentage of insulin-dependent New Yorkers, state-wide data was unavailable. However, a 2018 NYC Department of Health community health survey showed that 27.2% of diabetics age 18+ report taking insulin, or 3% of the NYC population<sup>6</sup>. Since this city data excluded all pediatric insulin users, and population density is most concentrated in NYC, we extrapolated this percentage to serve a state-wide estimate: **~3% of the total New York State population is insulin-dependent.** Based on 2019 population<sup>7</sup>, that is 583,607 people, or approximately **half a million New Yorkers need insulin.**

Without insulin, insulin-dependent diabetics suffer major complications including blindness, kidney disease requiring dialysis, amputation, diabetic ketoacidosis and early death. Not only is this excruciating for quality of life,

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<sup>1</sup> <https://insulin.substack.com/p/fight-messaging-with-data>

<sup>2</sup> <https://www.healthpeople.org/management-team/>

<sup>3</sup> <https://www.americashealthrankings.org/explore/annual/measure/Diabetes/state/NY>

<sup>4</sup> [https://www.health.ny.gov/statistics/prevention/injury\\_prevention/information\\_for\\_action/docs/2018-09\\_ifa\\_report.pdf](https://www.health.ny.gov/statistics/prevention/injury_prevention/information_for_action/docs/2018-09_ifa_report.pdf)

<sup>5</sup> <https://www.americashealthrankings.org/explore/annual/measure/Diabetes/state/NY>

<sup>6</sup> <https://a816-healthpsi.nyc.gov/epiquery/CHS/CHSXIndex.html>

<sup>7</sup> <https://www.census.gov/quickfacts/fact/table/NY/PST045219>

but this is incredibly expensive to the state: **Diabetes costs New York an estimated \$12 billion a year in direct medical costs and lost productivity for all payers, including Medicaid**<sup>8</sup>. Diabetes and prediabetes cost an estimated \$21.6 billion in New York each year.<sup>9</sup>

In recent years, there has been a significant increase in the rate of diabetes amputations, as well as premature and preventable deaths of people with diabetes caused directly by the lack of access to affordable insulin:

- **Since the 1990s, the cost of analog insulin has increased over 1,200%**<sup>10</sup>, yet the cost of production for a vial of insulin is between \$3.69 and \$6.16<sup>11</sup>.
- Annual average spending by people with diabetes on insulin nearly doubled from 2012 to 2016, **increasing from \$2,900 to \$5,700**<sup>12</sup>.
- **Non-traumatic amputations have increased among young U.S. diabetic patients aged 18-44, reversing a twenty year decline**<sup>13</sup>.
- **At least 1 out of every 4 patients with type 1 diabetes have had to ration their insulin due to cost**<sup>14</sup> **Some have died**<sup>15</sup>.

We support the passage of S.6492-A (Rivera) / S.8533 (Joyner), which includes the \$100 insulin co-pay cap, emergency prescription refills, and the drug assistance demonstration program / emergency insulin access. These three components function together, and are integral, in order to protect diabetic New Yorkers and build long term health, and health savings, for New York State. We also support any further programs or legislation to continue to make insulin affordable and accessible for all diabetic New Yorkers.

### **1. Emergency Prescription refills (aka “Kevin’s Law”)**

This will assist people who run out of prescription refills by authorizing a pharmacist to dispense an emergency supply of a chronic maintenance drug, like insulin. Advocacy for emergency prescription access began in 2014 when Kevin Houdeshell was turned away from a pharmacy due to an expired prescription and died shortly after when the pharmacy could not reach his prescribing doctor over a holiday weekend.

### **2. Insulin co-pay cap at \$100/month**

This will help diabetics who have employer/marketplace insurance to afford the insulin they need. About 27% of the state’s total population would be eligible for the co-pay cap, or 155,000 New Yorkers that would be supported through this. This will prevent unnecessary medical debt, insulin rationing, and ultimately, the tragic suffering caused by complications and early mortality. It will also save the State significant amounts of money, as hospitalizations related to complications with diabetes cost nearly \$1 billion per year.

### **3. Drug assistance demonstration program**

This may assist New Yorkers who are uninsured or underinsured, within 400% of the national poverty line (NPL), and those who are not eligible for the co-pay cap. This will save billions immediately from emergency room visits. Decades down the line, savings are recouped from proper management of treatable diabetes complications, and will

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<sup>8</sup> See New York State Medicaid Redesign Team Waiver Amendment Request, page 90, available at [www.health.ny.gov/health\\_care/medicaid/redesign/docs/2012-08-06\\_waiver\\_amendment\\_request.pdf](http://www.health.ny.gov/health_care/medicaid/redesign/docs/2012-08-06_waiver_amendment_request.pdf).

<sup>9</sup> <http://main.diabetes.org/dorg/PDFs/Advocacy/burden-of-diabetes/new-york.pdf>

<sup>10</sup> <https://www.patientsforaffordabledrugs.org/2019/11/14/tar-insulin/>

<sup>11</sup> <https://gh.bmj.com/content/3/5/e000850#T1>

<sup>12</sup> <https://healthcostinstitute.org/research/publications/entry/spending-on-individuals-with-type-1-diabetes-and-the-role-of-rapidly-increasing-insulin-prices>

<sup>13</sup> <https://www.ncbi.nlm.nih.gov/pubmed/30409811>

<sup>14</sup> <https://news.yale.edu/2018/12/03/one-four-patients-say-theyve-skimped-insulin-because-high-cost>

<sup>15</sup> <https://www.t1international.com/in-memory/>

protect New Yorkers from the trend of early mortality for diabetics seen across the United States due to insulin rationing as prices continue to rise. Up to 135,000 diabetic New Yorkers could be supported through this program.

Access to affordable insulin is a life and death issue for many New Yorkers. The price-gouging of this essential medicine is causing immense pain and loss of life at high expense to tax-paying New York residents. S.6492-A / A.8533 is a comprehensive bill that will bring great relief to New Yorkers while efforts continue to create a federal solution to the unaffordable prescription medicine crisis. We urge the Legislature to pass this common-sense life-saving and cost-saving legislation, and to continue to develop and expand programs to ensure a steady and affordable supply of insulin, related supplies, and other life saving medications, and urge the Governor to sign it into law.