A Letter to the High Deductible Task Force

December 17, 2019

To the members of Connecticut’s High Deductible Task Force:

The Connecticut #insulin4all chapter — supported by T1International — is a group of volunteer advocates raising awareness about the insulin price crisis and fighting for insulin pricing transparency and affordability in Connecticut.

We have seen first hand the detriment that high deductible insurance plans have had on our members in the state. Many individuals have expressed their struggle with affording the exorbitant list price of insulin before they meet their deductible.

My own work with this organization began because of a high deductible insurance plan. After turning 26 and being forced off of my parent’s insurance, I knew I had to get an insurance plan that would offer adequate coverage for my type one diabetes care, medication, and supplies. In the end I went with a plan which had a deductible equal to my entire month’s salary. My hope was that I could slowly chip away at the deductible so I could get my necessary items covered.

What I didn’t anticipate was the exorbitant out-of-pocket costs for insulin. As I began researching all the different ways for financial assistance, I stopped going to the doctors. I started reusing my diabetic necessities such as needles and insulin pump supplies. Ultimately, I started rationing my insulin for months, hoping to make every life-saving drop last until I found a viable solution.

However, that viable solution never came. I called my insurance company, the pharmaceutical company, patient assistance programs, and all the prescription coupon companies I could find. Yet, I met the same response every time: they couldn’t help me because I had insurance. Albeit, an insurance that couldn’t prevent me from rationing the one thing that saves me from an excruciating death.

Though I have a decent insurance plan now, I am terrified of what the future may bring. If I had a high deductible insurance plan before, what prevents me from ending up in a similar plan in the
future? I hear this concern reiterated with almost every member I speak with, especially with parents of diabetics.

These concerns aren’t unfounded and they aren’t rare — a Yale study found that 25 percent of type one diabetics in New Haven county reported rationing their insulin. Another survey by UpWell Health found almost half of those surveyed have rationed their insulin. It’s not difficult to draw conclusions as to why this is occurring: the Health Care Institute found that out-of-pocket spending by patients with type 1 diabetes on insulin nearly doubled from 2012 to 2016, increasing from $2,900 to $5,705.

We believe the rising costs of insulin and other pharmaceuticals are significantly contributing to the prevalence of high deductible health plans. Since the 1990’s the cost of insulin has increased 1200 percent, far exceeding the rate of inflation.

These times require courageous action; it is time we do not let fear dictate our behavior and instead choose bold moves to protect the citizens of Connecticut. For too long Connecticut residents have had to bear the majority of the burden of our health system’s inequities.

This task force represents an incredible chance to change this. The Connecticut #insulin4all chapter would like to encourage the High Deductible Task Force to keep in mind the contribution pharmaceuticals have on insurance plans. Pharmaceutical companies should be held accountable for their role in this crisis and full transparency should be sought. While insulin co-pay caps have been introduced in states such as Colorado to help limit out-of-pocket costs, patients still face some significant challenges. Those with high deductible health care plans aren’t always protected and insurance plans have found ways to charge more for those who require multiple insulins for their care. We also fear that these co-pay cap bills risk insurance companies raising premiums or deductibles to compensate for any losses.

While these co-pay bills are a step in the right direction for diabetics, we believe that Connecticut can go a step further. We ask the task force to consider a prescription drug affordability board, similar to the one Maryland recently enacted. The capping of pharmaceutical prices has the potential to change the landscape for insurance plans and, more importantly, for the residents of Connecticut.

We thank the committee for taking up this critical issue and for working to enact real, lasting changes for Connecticut residents.

Sincerely,

Kristen Whitney Daniels
Connecticut #insulin4all — Chapter Leader
The Insulin Affordability Crisis in the U.S.

- Approximately 30.3 million people in the United States have diabetes; of these, around 1.25 million have type 1 diabetes.
- There are over 7 million Americans that rely on injected insulin to stay alive & healthy.
- Since the 1990’s, the cost of insulin has increased over 1,200%, yet the cost of production for a vial of analog insulin is between $3.69 and $6.16.
- Spending by patients with type 1 diabetes on insulin nearly doubled from 2012 to 2016, increasing from $2,900 to $5,700.
- Over 50% of Americans on insulin risk paying the full list price – 8.8% of Americans are uninsured and 47% have high deductible insurance plans.
- One of every four patients with type 1 diabetes has had to ration their insulin due to cost; among young adults, from ages of 18 to 25, studies have shown that 43% have rationed.

Diabetes in Connecticut

- Approximately 355,000 people in Connecticut, or 11.4% of the adult population, have type 1 or type 2 diabetes.
- Every year, an estimated 18,000 people in Connecticut are diagnosed with diabetes.
- Total direct medical expenses for diagnosed type 1 and type 2 diabetes in Connecticut were estimated at $2.7 billion in 2017.
- Many patients in Connecticut are unable to afford insulin – which has had serious consequences.

"My son, Alec, died from rationing insulin. He could not afford the high cost. Why is it that, in America, the pharmaceutical companies set the price without justification?"

- Nicole Smith-Holt · Richfield, Minnesota
About T1International and #insulin4all

T1International is a non-profit organization run by people with type 1 diabetes for people with type 1 diabetes. We support local communities around the world by giving them the tools they need to stand up for their rights. Our aim is to empower advocates to ensure that access to insulin and diabetes supplies becomes a reality for all.

T1International takes no funding from pharmaceutical or diabetes device companies in order to avoid conflicts of interest and to ensure independent advocacy. We will continue to work with advocates until affordable insulin and diabetes supplies worldwide is a reality.

In 2014, T1International launched the #insulin4all campaign for World Diabetes Day. Over the years, the campaign and hashtag have grown into a larger movement, particularly in the United States as insulin pricing has created a crisis for Americans with diabetes. The movement intends to draw attention to diabetes and insulin affordability issues and it is used as a rallying cry across the United States and around the globe.

T1International’s first U.S.A. #insulin4all Chapters launched in 2018, and have expanded to 34 grassroots Chapters in states across the country. These Chapters are made up of volunteer advocates, who have been instrumental in bringing insulin accessibility issues to the spotlight by sharing their stories and working with lawmakers to pass meaningful legislation to address insulin access issues and the insulin affordability crisis.

About Connecticut #insulin4all

Minnesota #insulin4all is a group of volunteer advocates raising awareness about the insulin price crisis and fighting for insulin pricing transparency and affordability in Connecticut.

The purpose of the Connecticut #insulin4all Chapter is to promote awareness of the price-gouging practices of insulin manufacturers and the financial burden it creates for people with diabetes; to empower individuals impacted by the high price of insulin to share their stories and fight for change toward making life-saving insulin affordable; and to push for transparency and lower insulin prices to end the insulin price crisis. The Chapter is supported by T1International.