

July 21, 2020

Insurance and Real Estate Committee – Public Listening Session:
LCO 3601: An Act Concerning Diabetes and High Deductible Health Plans
Kristen Whitney Daniels, Connecticut #insulin4all Chapter Leader

Dear Chairman Lesser, Chairman Scanlon, Ranking Member Kelly, Ranking Member Pavalock-D'Amato, and distinguished members of the Insurance and Real Estate Committee:

I am Kristen Whitney Daniels, the chapter leader of T1International's Connecticut #insulin4all chapter — a group of volunteer advocates raising awareness about the insulin price crisis and fighting for insulin pricing transparency and affordability in Connecticut. We do not accept pharmaceutical industry funding or any funds that would compromise or influence our ability to advocate. I am also a Shelton resident, who has type one diabetes.

I am testifying today in support of LCO 3601: An Act Concerning Diabetes and High Deductible Health Plans, while asking for some critical improvements to the bill.

This bill represents an important first step in curbing the out of control costs that affect people with diabetes in the state of Connecticut. This bill will also provide people with diabetes immediate access to their insulin in emergency situations. Additionally, we acknowledge the promise of a working group to determine how federal programs can be leveraged to further assist people with access to insulin.

For too long, Connecticut residents have been paying the literal and figurative cost of the high price of insulin and diabetes related supplies. It is this chapter's hope that this bill will be the start of meaningful change for people with diabetes in Connecticut and addressing the exorbitant pricing of prescription drugs.

A 2019 study done by U.S. Senator Richard Blumenthal's office of 50 pharmacies in Connecticut saw the list price for a single vial of insulin cost anywhere between \$274.00-\$446.78. Most people with diabetes require multiple vials of insulin a month and some require more than one insulin for their care. It's not surprising with those prices that [out-of-pocket spending](#) on only insulin for people with type one diabetes nearly doubled from 2012 to 2016, increasing from \$2900 to \$5700. This number doesn't take into account the test strips, glucose meters, glucagon, needles, ketone test strips, glucose gels, insulin pump supplies, continuous glucose monitors, lancets, alcohol swabs, and the many more items people with diabetes may require to safely make it through the day.

There is no good reason for insulin to be this expensive. Insulin isn't a new drug; it was discovered in 1922. It was never meant to be an expensive drug; the patent was sold for \$1 as a "gift to mankind." Yet, pharmaceutical companies realized the gold mine they sat on. Patients who require insulin have no choice — you buy insulin, or you face an excruciating death. Since the 1990's, the price for insulin has risen [1200%](#), yet the estimated cost to manufacture a single vial of analog insulin costs between no more [\\$3.69-\\$6.16](#).

There are serious consequences that come from such high list prices. A Yale study found that [one in four patients](#) with type one diabetes has had to ration their insulin — the dangerous practice of cutting back on the recommended dosage of insulin, which has led to many deaths. In addition to rationing, people with diabetes have resorted to other extreme measures like

choosing between buying their essential insulin and other diabetes related supplies or paying their rent, buying food, or making other unthinkable sacrifices.

If you know a person with diabetes, you likely know someone who has had to make these “unthinkable sacrifices.” In fact, I am one of those people — I have gotten to the bottom of my insulin vial and questioned whether I was going to afford my insulin or my rent or my food or my car. I spent hours upon hours calling my insurance company, my insulin manufacturer, and every prescription coupon assistance plan I could find. None of those “solutions” worked for me; each offered sympathy with no answer on how I was going to see the next day. I was lucky enough to find a federally qualified health center to treat me; however, many people do not have the resources nor the time to search for solutions when facing the end of their vials.

If we look at Connecticut as a whole, we know the proposed legislation has the possibility to help many residents — and the government — save a significant amount of money. Approximately [355,000 people in Connecticut](#), or 11.4% of the adult population, has been diagnosed with diabetes. For these people, their medical expenses already cost 2.3 times higher than for those without the disease. In 2017, direct medical expenses for diagnosed diabetes in Connecticut was estimated at \$2.7 billion. This means, on average, a person with diabetes in Connecticut could expect to pay \$7605 a year for just this singular disease. Diabetes isn’t solely a fiscal impact on the individual and family; it also amounts to significant costs for the state. Diagnosed diabetes costs the state of Connecticut an estimated \$3.7 billion every year.

No person with diabetes in the state of Connecticut should be forced to forgo their insulin, their blood glucose strips or critical health care treatments because of high health costs. The \$25 out-of-pocket cap on insulin and \$100 out-of-pocket cap on supplies — the first proposed supplies cap in the country — is a great start to help protect people with diabetes. I appreciate the bill’s acknowledgement of diabetes supplies, as costs have risen dramatically for the complex treatment of diabetes. This bill will be a tremendous relief for individuals and families on individual insurance, small group insurance and those covered by large group fully insured plans, which makes up [roughly 28% of plans in Connecticut](#).

The emergency refill portion of the bill — which is commonly known as Kevin’s Law, named Kevin Houdeshell who tragically died in 2014 because he could not refill his insulin over a long weekend — will provide another safeguard for people with diabetes, as well as pharmacists. The Connecticut #insulin4all chapter recommends lawmakers consider a 30-day supply of the medication/diabetes supply that can be accessed up to twice a year. We would also like to see this bill extend to any other medication, such as inhalers and epi-pens, that does not come in the standard 72-hour dosage that the current Connecticut statute requires. We also express concern over the electronic prescription drug monitoring program outlined in sections 4 and 5. This program could create additional barriers for patients — the very thing the bill is attempting to eliminate for patients in emergency situations.

We’d be remiss if we didn’t mention the most glaring admission from this bill — assistance for uninsured and those on high deductible health plans. We are extremely disappointed to see no immediate assistance for people who are uninsured or underinsured in the state of Connecticut. When we look at truly effective bills, it is critical that we ensure the most vulnerable are protected. Unfortunately, this bill does not provide immediate relief to the many residents in Connecticut who are forced to pay the list price on insulin. While the bill makes critical first steps for people with diabetes, the co-pay cap only assists people on certain insurance plans. In previous versions of this bill, there was a provision to create a taskforce to study how to assist these individuals. While we believe it is not enough to just study how to assist the uninsured,

rather than receive no assistance at all, we would like to propose that the Department of Social Services working group also be tasked with finding a mechanism to ensure no one goes without their insulin. The group could explore ways to implement a program similar to the [Alec Smith Insulin Affordability Act](#) and find a funding mechanism that ensures that insulin manufacturers are held accountable for the crisis while also being made part of the solution.

We are incredibly appreciative of the inclusion of advocates on the Department of Social Services task force, as we believe they will provide valuable insight and lived experience. These advocates will be integral in ensuring that this program does not become another patient assistance program that creates additional access issues, like the patient assistance programs insulin manufacturers already tout as a solution. Lack of affordable access to insulin is a life-threatening issue, one that cannot be stalled by laborious amounts of paperwork and navigating complex systems. That said, the study of leveraging the 340b program, Federally Qualified Health Centers, and a Medicaid waiver to assist low-income individuals has the potential to help many residents. Diabetes [disproportionately affects people of lower socioeconomic status](#) in Connecticut. In 2012, adults with incomes less than \$35,000 were over twice as likely to have diabetes as compared to those with incomes of at least \$75,000.

The statistics and numbers from the insulin pricing crisis are harrowing. They require swift and courageous action from our elected officials to prevent more deaths and more complications. We are thankful that the proposed bill has the chance to help many Connecticut residents. It marks an incredible first step in making insulin for all. But now is the time to not let fear dictate our choices and instead choose bold moves to protect all citizens of Connecticut. For too long Connecticut residents have had to bear most of the burden of our health system's inequities. For this reason, we ask that the committee consider how to ensure all citizens in the state have affordable access to insulin, namely the uninsured.

I respectfully ask the committee to pass **LCO 3601: An Act Concerning Diabetes and High Deductible Health Plans** and consider the revisions outlined above.

Sincerely,

Kristen Whitney Daniels
Connecticut #insulin4all Chapter Leader