

I'm here to submit testimony in support of the insulin pricing bill. My name is Samantha Merwin and I live in Haddam, CT. My child Logan Merwin has been living with Type 1 Diabetes for 12 years. For most of his life we have been impacted by the cost of insulin and diabetes supplies. He was diagnosed in 2008 and every year we spend over \$5000 in covered and not covered medical expenses (for the record, we are at over \$3500 for this year so far). This doesn't include the monthly premium cost of insurance which brings our total out of pocket medical costs annually to double that.

I support the price cap for insulin and diabetes supplies for Type 1 patients regardless of insurance plan. The Type 1 community has been held hostage for years by the insane cost of insulin, which is why rationing occurs and people die. It's important for all of you to know that we have no choice but to buy insulin, a human with Type 1 will die without it. Type 1 diabetes is unique in that there is no generic alternative or other treatment available.

Our family has been on a high deductible plan for most years with varying out of pocket maximums. I previously testified what our insulin costs were in 2018. As an update, on March 5 2020 we needed to order insulin for Logan and went to a retail pharmacy. We attempted to get assistance through the programs offered by Novo Nordisk but didn't qualify for the low cost program and the coupon on file for the other program actually made the insulin cost more since it only applied to one month. We wound up ordering the 3 month supply through mail order at a cost of \$1169.59. So for anyone that tells you that insulin discount programs are out there, please realize that we, among others, were not able to qualify and access them when we needed them most. There is a copay cap program in our pharmacy coverage but it doesn't apply to our insulin. I could have gone to Canada or pursued further but the Covid crisis was starting and I needed to have it on hand. This specific legislation may not help those on all insurance plans but it's a start and I'm confident that CT will go further with additional legislation to help all patients. Most years I pay for the first shipment of pump and continuous glucose monitor supplies in January, to pay it off in December only to have it start over again in January.

I'm extremely passionate about supporting the language in the legislation for Kevin's law. Pharmacists should be allowed to dispense a 30 day supply of insulin if the prescription has expired. The language should be clear about the one month supply as there have been issues under the current 72 hour legislation. Insulin is not dispensed in the existing quantities and there have been several examples of families being turned away at the pharmacy in this scenario. On 10/10/2017 I was sitting at home when I saw a post on social media and made contact with a lady across the country whose cousin lived in the next town over and had no insulin left. He went to the pharmacy but hadn't been to his doctor in

a while so didn't have a valid prescription on file. We gave him some of our emergency supply and made him promise to go to the doctor soon. His alternative was to incur more debt and go to the emergency room for treatment or prepare for death. That night had a huge impact on me, I never want this to be my child.

As I mentioned at the press conference our family should have been directing our savings to Logan's college fund, instead we focus mostly on a medical savings fund for his young adult years. We fear regularly that he may not be able to afford the costs of his diabetes care which will be outrageous by that time unless our elected officials do something to stop the price increases. I wholeheartedly support the idea of a medicaid waiver whereby a Type 1 patient would be able to join a Medicaid plan to access their supplies for less out of pocket. I'm confident that's an excellent solution to tackling the entire out of pocket cost of Type 1 Diabetes.

Every single one of you knows someone impacted by Type 1-they are your constituents, your family members and your neighbors. Please support this legislation to help them. If enough states enact legislation that caps these costs, the federal government will need to do something that impacts everyone, including self insured plans.

It's important to note that while you are hearing consistent messages and stories from our Type 1 community, we aren't asking for anything for free. We are just asking for fair. **Fair not free.**

Thank you for your time today and your support of this bill that's so important to my family.