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Testimony to the Committee on Insurance & Real Estate

Dear Committee Co-Chairs, Vice Chairs, Ranking Members and Honorable Committee Members,

Thank you for considering LCO No 3601 and for the opportunity to tell my family's story. I strongly support these bills. There is room for improvement, but these bills are a huge leap forward for every person who relies on an insulin prescription to stay alive.

I support a price cap for monthly supply of insulin. I support a price cap for noninsulin medications like glucagon needed to manage diabetes. I support a price cap for diabetes related supplies. I support allowing pharmacies to provide emergency refills of insulin and diabetes supplies.

I would love to see the definition of "Diabetes equipment and supplies" expanded to include insulin delivery supplies including insulin pumps, pump sites, blood glucose monitoring systems like continuous glucose monitors (CGM) and sensors. These too are life saving critical supplies for people with diabetes.

I would also like to see these provisions apply to all state regulated plans, not only high deductible plans.

I live in Kent, Connecticut. My husband and I have three children. Our son Myers and daughter Beatrice are ten-yearold twins. Our son, Eben, is seven years old. My husband and I both work for 501c3 non-profit land trusts working to conserve natural resources for the benefit of and use by current and future generations. We believe that working for the benefit of the public, as well as the natural world, is a critical service for our community.

Our incredible daughter, Beatrice, was diagnosed with Type One diabetes on March 10, 2014. It has been 2,325 days. Since that day we have had an invisible influence on <u>everything</u> we do. Each day a person with diabetes, or in the case of a young child, the parent or caregiver, makes an estimated two hundred additional decisions over someone who is not affected by diabetes. Calculating insulin dose, calculating carbs, thinking about how something (food, activity, mood) would affect blood sugar, communicating with someone about a treatment decision (high or low blood sugar), explaining some aspect of diabetes to someone else, looking at CGM, waking up in the middle of the night to treat a low or high blood sugar. These decisions include dosing a medication, insulin, that is life-saving, or can kill, and costs so much many families have to choose between it and food. These decisions must be repeated multiple times a day. Every day. For the rest of their lives.

Beatrice was four years old when she was diagnosed. She was having bouts of nausea, was losing her hair, was losing weight, and was insatiably thirsty. She was twenty-seven pounds. She was small to begin with, but an average four-year-old would be forty pounds. We were so lucky that night to have caring doctors who stayed late and kept her out of the hospital. I gave my tiny, sick daughter a shot for the first time that night. I filled the six prescriptions we now needed to keep our daughter alive. We were lucky to be on Husky health insurance at the time, so I did not have to weigh the cost of these prescriptions and appointments. We could just do what needed to be done to care for our daughter. I gave her six more shots on the first full day and pricked her skin for a drop of blood and check her blood sugar at least ten times.

About seven weeks later she got her first insulin pump. This tool improved her quality of life immensely. We did not have to count and limit carbs in the same manner as we did when she was on shots. We had more flexibility and more control. And best of all, instead of needing six to eight shots per day, we changed her pump site once every three days.

That summer we went on a family vacation. On the way home from a great time, the whole family was sleeping while I drove home. Beatrice woke up and, although her speech was difficult to discern, began to tell me that the car was "filling up with poison water." Her whole body was twitching. Her eyes were unfocused. She was having a seizure. I was able to pull off the highway into a rest stop immediately and woke my husband. He delivered an injection of glucagon. We checked her blood sugar to ensure hypoglycemia is what was causing the problem. It was thirty-four. It is supposed to be one hundred. Her brain was being starved of the fuel it needed to function. She could easily have sustained brain damage or even died that day if was did not have glucagon with us.

Soon after, Beatrice got her first CGM. This is a monitoring system that reads blood glucose every minute, averages the results every five minutes, and sends the information to a receiver. The receiver then displays both a blood sugar number and a trend (falling, staying steady, rising). Since then Beatrice has had terrific control of her diabetes. We can make better treatment decisions and lower her risk of another hypoglycemic seizure to almost zero because of this tool. It is critical at all times, but especially at night when Beatrice's blood sugars are most unpredictable and we cannot use her behavior and symptoms as a guide, while she is at school, and while she plays/exercises.

In 2018 our household income was over the Husky threshold by a few thousand dollars, so we had to purchase a PPO plan using Access Health CT. That year we paid \$3,679.40 for pump and CGM supplies and \$953.93 on prescriptions. This does not account for glucose tabs, juice boxes, alcohol preps, Skin Tac, Unisolve, and lancets. It also does not include premiums, doctor visit co-pays, or lab work. The expenses our family had to pay to keep our daughter alive and healthy added up to far more that the amount our income exceeded the Husky threshold by. Luckily our children were back on Husky in 2019 and 2020 although we still shoulder significant debt we had to take on in order not to disrupt Beatrice's prescriptions, supplies and medical care.

No matter what insurance we have, we must rely on an opaque and burdensome system including prescriptions and prior-authorizations in order to get life saving medical supplies for a condition for which there is no cure. This does not make sense. We have come very close to having to borrow insulin and supplies from other families with Type One. We are lucky to have such a supportive community to rely on, but we should not have to. Insulin is necessary for life. If the insurer says they have not received the faxed paperwork the doctor says she sent and therefore the pharmacist cannot dispense insulin, the patient will be hurt. This scenario has happened to every Type One family I know. There is no need for this. One cannot abuse insulin.

I support a price cap for monthly supply of insulin. I support a price cap for noninsulin medications needed to manage diabetes. I support a price cap for diabetes related supplies. I support allowing pharmacies to provide emergency refills of insulin and diabetes supplies.

Please take action to support insulin dependent people and their families. Please pass Senate Bill 1 and House Bill 1575. Lifting some of the financial burden caused by this condition will allow families to concentrate on staying healthy, not go into debt in order to stay alive and contribute to their community and society in ways that are not possible now.

Thank you for your time in considering these bills and again for the opportunity to tell my family's story.

Yours Sincerely,

Amanda Branson