

Jordan Roylance

Died December 2018

Our oldest son, Jordan, was found collapsed on the floor of a garage December 8, 2018. His cause of death was attributed to diabetic ketoacidosis (DKA), a result of a high blood sugar level. He would've turned 38 three months and 1 day later.

He was first diagnosed with Type I diabetes at the age of 15. We were fortunate that my job provided health insurance for all of my family. This gave us affordable medical care, including insulin and test strips for Jordan. However, after he turned 26, he was no longer eligible for my insurance. Since his different construction jobs did not provide insurance, he managed his diabetes by carb-counting and "ball-parking" his insulin dosages. Neither the insulin nor the test strips were even close to affordable for him, especially without insurance. **As a result, he was rationing his Walmart, non-prescription insulin.**

When his body was discovered, he had half of a vial of insulin just a few feet from where he was found. We can only surmise that as he felt the symptoms of DKA coming on, he stood up to get his insulin and passed out.

He was familiar with DKA as he'd had several bouts previously and his wife had always been nearby and able to get him to the ER. However, they didn't have insurance and the medical bills became too much for them. The financial pressure contributed to their crumbling marriage and they filed for divorce in 2016. Since he was now living alone, no one was aware that he'd passed out.

He was last seen alive on Tuesday, December 4; his body was discovered Saturday night, four days later.

Had he had access to affordable insulin, he would not have had to ration and would most likely still be with us today. Now we are left with memories and a little anger. But we are blessed to be raising his 16 year-old daughter. We all miss him terribly.



*story courtesy
of Thom
Roylance,
Jordan's
father*

HB207 – Insulin Access Amendments



Our Stories

Chris Brunson

In 1999, at the age of 13, I noticed the symptoms of what I would later learn was Type 1 Diabetes. I needed to use the bathroom many times a night and that I also could not drink enough water. More than that, I felt miserable all the time.

When I turned 18, in 2002, life as a Type 1 diabetic became infinitely more difficult. My mom had just passed away a week before and along with the insurmountable loss of my mom I became legally responsible to provide for my own healthcare. I needed test strips, syringes among many things but most importantly, insulin. However, I couldn't get health insurance. I realized very quickly I was going to have to change my goals for my life in order to just survive.

I delayed going to college for 2 years even though I had a 4-year full ride scholarship. During that 2 years I worked 2 jobs, sometimes 3 jobs at a time to try and support myself. Even still, during this time, **I found myself having to choose between food or insulin.** Eventually things worked out to where I was able to start attending college full-time (which was a requirement of my scholarship) but I also had to continue to work a full-time job with additional jobs during the summer to try and stay afloat. It was hard and getting harder to pay for insulin and I continued to have to make choices to either ration insulin, buy less food, or work even more hours.

I wanted to go on to graduate school but realized there was no way I would be able to afford it, as the price of insulin and other necessary medical supplies continued to climb. So, I put my head down and continued to work 2 or more jobs. We made hard choices each month about what bills to pay and what medical supplies to buy, but during all these years, **as I worked harder and harder to try and survive, rationing insulin, rationing food, going without things most other young couples had.** I could not keep my blood sugar in control without access to insulin and therefore keep my whole body healthy because **I couldn't pay for the one thing I needed. Insulin.**

In 2014, at the age of 30, with no prior family history, I had a **series of multiple heart attacks over a weeks' time without any typical symptoms.** This led to many problems with my heart, particularly Congestive Heart Failure. The cardiology team didn't believe I would live through the first night. When I spoke to the cardiologist a couple days later, and I told him about how my blood sugars were uncontrolled for all these years because I couldn't consistently access insulin. He told me he absolutely believed this was the reason I had this happen to me.

No one should see their hopes, their dreams, their goals, their family, their LIFE lost because they cannot afford a medicine, the only medicine, which keeps them alive. I am now disabled permanently because I didn't have access to insulin. I don't want to see a single person have to suffer because an autoimmune disease attacked their bodies to no fault of their own.



Casey David Domgaard

Died January 2020

Casey David Domgaard was an amazing son, brother, uncle, and friend. When he saw a need, he was the type of person who would give you the shirt off his back. On January 7th, 2020, my amazing brother left this earthly home at the young age of 36. Losing a brother is heartbreaking, **but losing a brother when his death could have possibly been prevented is almost unbearable.**

Casey developed Type 1 Diabetes when he was 15 years old. The cost of his medical bills and medications were hard on my family, but as Casey became an adult, this burden became an even bigger struggle for him. **He spent roughly \$800 a month on his insulin.** Casey was a hard worker and was adamant about being independent. He never asked for a hand-out but worked hard and paid daily to stay alive. In 2015, Casey became blind. This prevented him from being able to work and he was on a waitlist for 2 years to get disability. He sold everything he had to keep up with the rising cost of his medical care and insulin.

Casey had a conversation with a friend just days before he passed away and let them know that he had gone 2 weeks without insulin. He assured them that he had it under control. By "under control" he meant that he thought that he could stretch it just a little longer.

Diabetes affects roughly 30.3 million people. My biggest prayer is that changes are made so that nobody else has to bury a loved one due to a lack of insulin. Nobody should be sentenced to death simply because they can't afford a medicine that they need to survive.

I am pleading with you to please support house Bill 207 because nobody should have to bury their mother, father, sister, friend, or brother because the cost of insulin was just too high for them to survive.

story courtesy of Tiffany Warren,

Casey's brother

Jackson and Chrystal Klewein

My 14 year-old son was diagnosed with type 1 diabetes when he was 8 years old. Recently, he let me know he was out of both his fast-acting as well as his long-lasting insulin. I called our pharmacy to get his prescriptions refilled. I was told that they could refill the fast-acting insulin but not the long lasting as it was too soon. At some point, my son had lost one of the insulin pens, thus needing a refill. I was not eligible through my insurance to get a refill until weeks later.

Without these medications, type 1 diabetics are faced with diabetic ketoacidosis, which requires hospitalization, possible coma, swelling of the brain, and even death. My son had already left school early this morning as he had not been able to take that long lasting insulin last night due to being out and was not feeling well because of it. I called my insurance company, Regence Blue Cross Blue Shield and was informed that "under no circumstances" can they approve a refill because of lost medication. I was told that I would be responsible to pay 100% for replacement insulin or have my son go without until a refill was available. A five pack of the insulin pens is \$316.85 and the majority of pharmacies will not open a box so that only one or two pens may be purchased. I would have had to buy the entire box of five.

Luckily, I was able to contact his endocrinologist's office at Primary Children's Hospital and pick up a vial of a different long-lasting insulin. My concern is, what if they hadn't of had any vials available for me to get? **I do not have the \$317 to just go buy some more insulin.** What if I was in a situation where there was no possible way for me to replace the insulin until the insurance would cover it again? Are we as parents supposed to skip buying groceries or miss a utility bill, car payment, etc. in order to keep our children alive? I feel as though denying the coverage of insulin should be criminal. My son, specifically, can end up in ketoacidosis and admitted to the hospital after as little as two days without that insulin. **This is a LIFE SUSTAINING medication that type one diabetic children nor adults can be without.**

There should never be any reason that insurance can refuse coverage of a medication that is required to keep someone alive. Additionally, IF the insulin did not cost so much, we, as working, tax paying citizens might be able to afford an emergency replacement. I work 7 days a week between two jobs and there is still no way I would be able to afford the added expense of this medication. We lose numerous type 1 diabetics each year who have aged off their parent's insurance and cannot afford their insulin. They either go without or end up rationing the insulin they do have. Neither case is acceptable. **There needs to be a change.**



Story courtesy of Chrystal Klewein, Jackson's mom

Stephanie Arceneaux and family



I was diagnosed with Type One Diabetes in December of 1984.

Nothing could be done to predict or prevent my chronic disease. I will live with it every second of the day until the day I die. **It has had a huge impact on my life because of its omnipresent nature.**

When I met my husband in 2011 and learned that he also had T1D, I was relieved that I had met someone that entirely understood the weight of having this disease. When we decided to have a baby, we consulted doctors who told us that the chances of our child having T1D, even with two parents with the same disease, was about 10-25%. The two of us decided to go forward with our plans to start a family.

A year and a half ago we found out that our son did not escape our disease as we had hoped he would. At that time, my husband and I were already struggling to afford our insulin and other needed diabetes supplies. I had started to accept donations of insulin from strangers to get us by. I was eating only twice a day and my husband was reusing supplies that are meant to only be used once.

Forty percent of our income was and is going to just keeping us alive. That is before food and shelter.

Once our son was diagnosed, I became even more terrified. If we were struggling so hard to keep afloat now what would that look like adding a third person with diabetes to the mix? **My husband and I would sacrifice every last drop of insulin we have for our son, but we should not have to.** Our son deserves to have two living, healthy parents. And, he deserves a future filled with possibilities, not such a struggle to be able to afford what he needs to stay alive.

Q&A: How will HB207 make a difference?

Q: How does HB207 reduce costs for patients who rely on insulin?

A: Patients need immediate relief for out of pocket costs. Excessive insulin costs are currently putting lives at risk. HB207 does NOT require copay caps on insulin across the board. Instead, it lays out options for insurance companies to simultaneously reduce the out of pocket cost burden for patients, while creatively and competitively addressing prices. This is a crucial element to HB207 and sets it apart from other pieces of legislation that only implement a price cap. If insurers refuse to offer insulin without a deductible, on the lowest copay tier (or a proposal with equal cost-reduction) then they will be subject to a \$30 per month, per prescription, copay cap. Creating immediate relief for patients is an important first step in solving this issue.

Q: Why is it important for PEHP to use bulk purchasing for insulin?

A: Setting up bulk purchasing of insulin is an essential part of HB207, and any long-term solution to the high cost of prescription drugs. Bulk purchasing, in theory, allows states, or any buyer, to receive a better deal on a drug if they buy in a larger quantity. States have been banding together to do this for many years. Directing PEHP to set up a bulk purchasing program for insulin would provide long-term cost relief to patients and to the state. This would also provide additional cost relief to patients who are uninsured or self-insured, with the ability to buy insulin through PEHP with a discount card.

Q: How do pharmacy counter changes in HB207 improve access to insulin for patients?

A: Health care access barriers go far beyond prescription drug costs. Patients with diabetes must cover insulin copays, supply costs, copays for doctor appointments and labs—on top of premiums and deductibles. There are also numerous barriers with insulin and insulin supplies due to refill issues, paperwork errors, travel mishaps, and patchwork coverage of various brands and types of insulin and supplies. This all adds up to create a system that keeps patients jumping through hoops, making difficult decisions, and paying excessive costs, while the health care industry brings in money from many angles.

HB 207 makes changes that ease these access issues that quickly compound for patients. HB 207 increases the number of days a prescription can be filled and the length of time a script can last. Not only does this address the concern a patient has if they have an immediate need for insulin, and not the proper script, it will also decrease copay costs in the long term.

HB 207 Increases the number of professions that can be licensed to prescribe insulin. This provides needed flexibility for busy schedules, shortages, and copay cost variations. Patients will have more power over accessibility and price if they have more provider options.

HB207 also allows pharmacists to adjust the brand or type of insulin or diabetes supplies, using guidance and professional judgment. Physicians do not always know what prescription or supply an insurance company will cover, and so this way if a patient arrives to pick up a script and finds out it is not covered, the pharmacist could adjust the prescription and offer a covered equivalent without requiring another appointment, and copay, for the patient.

The Bottom Line:

Skyrocketing insulin costs are not sustainable for patients, and too many people are rationing, skipping doses, or even worse-- going without until it is too late. HB 207 not only creates limits on what patients will pay out of pocket for insulin, it also creates long term solutions to incentivize competition, lower cost, and increase access beyond copays for patients as well.