## Testimony Submitted by Paul Grant to the

## U.S. Senate Special Committee on Aging

## "Insulin Access and Affordability: The Rising Cost of Treatment"

## May 8, 2018

Good morning. Thank you Senator Collins, Ranking Member Casey, and members of the Senate Aging Committee. It is a privilege and an honor to be here to testify today.

My name is Paul Grant. I am a father of 4 children; Oliver (18 years old), Jordan (16), Solomon (13), and Levi (11). We live in the small community of Gray-New Gloucester, Maine. I would describe us as an active family. We play a lot of sports; basketball, baseball, soccer, football, lacrosse, and softball. We are usually on a field or in a gymnasium most days. My children mean the world to me, and I love coaching and watching them play.

At the end of January in 2014, my son, Solomon, became very ill. For at least a week, he laid on the couch with flu like symptoms. He was very lethargic, had stomach pain, grayish pale color, noticeably thinner, and he had glossy eyes. His mother had taken him to the doctors, but we were told he had the flu and it would just run its course. We treated him with ibuprofen and Tylenol, and made sure he drank lots of fluids. But Sol's condition did not improve. In fact, it only appeared to get worse. I was coaching youth basketball the day that I got a call from my wife. She was sad and upset because Sol was still very ill. She decided to take him to the ER at St. Mary's Hospital in Lewiston. My other three kids and I left basketball and met her at the ER. When I arrived, Sol was in a gurney, hooked up to an IV, surrounded by nurses. The on call doctor eventually came into the room and told us Sol had Type 1 Diabetes. His blood sugar was over 800. This was more than four years ago now, but I can remember this day like it was yesterday. You can imagine the feelings his mother and I experienced when we heard the words "Your son has Type 1 Diabetes." Our son has a disease. We experienced feelings of sadness, confusion, fear, astonishment and bewilderment just to name a few. The three of us spent that weekend in the ICU, and our lives were forever changed.

Today, Sol is 13 years old and a 7<sup>th</sup> grade student at Gray-New Gloucester Middle School. There are several students in the middle and high school that also have diabetes, and the school system does a pretty good job helping the students manage their disease. Besides going to the nurses' office several times a day to check his blood sugar and carrying around a diabetes bag, things are pretty normal for my 13 year old boy. He has a good group of friends, good teachers, and loves playing basketball. As long as he has insulin and checks his blood sugar regularly, he manages pretty well.

I work for a small General Contracting Company, Wally J Staples Builders Inc. We build new homes, additions, and garages. We also complete many interior and exterior renovations and pretty much anything to do with construction. I am a Project Estimator. I absolutely love my job, and have had the opportunity to be part of thousands of construction projects over the years. Unfortunately, like many small businesses, my employer does not provide health insurance, so I purchase it for myself and my children through the marketplace which is very expensive and very complicated. I have to pay a high

deductible to keep my monthly premium lower. Consequently, I end up paying a lot out of pocket for necessary supplies for Solomon, approximately \$2500.00 (+-) Last year, I will have spent close to \$15,000.00 for health care.

Solomon needs two types of insulin: Humalog and Lantus. In 2017, I would typically pay \$300.00 for a 90-day supply of Humalog through Express Scripts and around \$150.00 for a 90-day supply of Lantus. This seemed like a lot... until this past January when I called to refill Solomon's Humalog prescription. I was shocked to learn it was now going to cost more than \$900.00 for a 90-day supply. That's nearly \$1,000 for a treatment that Solomon absolutely needs, and about three times more than I had been paying. I immediately went into panic mode as I was low on Humalog and I had to get it as soon as possible. I tried to get answers from my insurance company but received little help or explanation. I don't think they even understand our health plan – I know I don't. I ended up purchasing a 30-day supply at Wal-Mart to get me by until I could figure things out. The 30-day supply cost me \$322.64 (with a coupon). I had no choice-- Sol had to have insulin.

No father wants to see what would happen if you run out of insulin for your child with Type 1. I remember Sol's state in the week that he was first diagnosed, when his body first stopped producing its own insulin, and I know that I must do whatever I can to make sure that he never has to go without it. I have purchased it on my credit card and I have had to borrow insulin from friends.

When I saw that the price had hiked to nearly \$1,000, I knew it was something I could not afford. I spent several hours and days reaching out to friends in the diabetic community looking for an affordable option. Ultimately, I found a pharmacy in Canada where I could purchase a 90-day supply of Humalog for \$294.97 which included a \$50.00 shipping fee. This is with no contribution from my insurance company. That was January 22<sup>nd</sup> and I just refilled that prescription the beginning of April with the same pharmacy in Canada. Last week, I checked with Express Scripts to see how much a 90-day prescription would be for Solomon's Humalog and it would cost me \$1,489.46 with my insurance.

As I mentioned, I help people build houses for a living. I am good at my job and can tell you very accurately how much it would cost you to build a new house or put an addition on your home – but I can't tell you how much it's going to cost from month to month to buy the insulin I need to help keep my son healthy.

I do not understand why Insulin for children with Type 1 Diabetes is so expensive and why I can purchase it in Canada for so much less. We are just talking about the cost of insulin today, but there are many other things like insulin pumps and glucose monitors out there that would make children's lives and parents' lives so much easier if they were more affordable.

Thank you again for the opportunity to appear before you today to share our story. I would be happy to answer any questions.