Proponent Testimony on HB 212

Chair Manchester, Vice Chair Cutrona, Ranking Member Liston, thank you for the opportunity to share proponent testimony on HB 212 which would extend coverage through the Bureau of Medical Handicaps to age 26 to mirror how long youth may stay on parents' insurance. My name is Cassandra Freeland, and five years ago this month my son Adam was diagnosed with Type 1 diabetes. Since his diagnosis, I have been involved in diabetes advocacy because it's what I know how to do, and it is one way I can help other people.

It is hard to explain the balancing act of this chronic disease to people who have not lived it. On paper, it looks simple: you take a shot of long acting of insulin or set a base rate on a pump, and then you count carbohydrates and dose mealtime insulin accordingly. In reality, it is much more complicated than that and we are making high stakes decisions on a regular basis, by ourselves, sometimes in the middle of the night. We are always weighing the other factors that affect blood sugar, such as the type of food, exercise, illness, and hormones of any kind (growth, reproduction, stress). We are always watching for changes in blood sugars and determining whether we need to change insulin dosage.

I can tell you this as a parent…When your child is diagnosed with type one diabetes, you worry about keeping them alive in the beginning, especially if they don't wake up for their low or high blood sugars. Then you worry about their ability to keep themselves alive. Managing this disease comes with a cost, not just the balancing act I described but the very real financial cost. Insulin prices have skyrocketed. Since 2009, the cost of insulin has gone from $40 a vial to around $300 a vial with no change in the product. An estimated 80% of this cost is accounted for by pharmacy benefit rebates. (Despite what some people many indicate, WalMart insulin is not an answer). Test strips are outrageously expensive when you consider what goes into them. Even with insurance, Type 1 diabetes costs can easily reach and even exceed $1,000 a month. This is a great article entitled "It's Not Just Insulin: Diabetes Patients Struggle to Get Crucial Supplies."

There is technology that makes managing this disease easier and safer, but it comes with a price. Our family and many other families now use a continuous glucose monitor. This is a device that is inserted and worn in the body for ten days and it measures the blood sugar every five minutes and sends that data to a phone or a receiver. Insulin pumps make it easier to control the dosage of insulin by allowing the user to adjust insulin delivery over the course of the day and to avoid 6-10 injections a day. There are now systems that allow these two devices to talk to each other and automate insulin delivery. Two have received FDA approval, another is awaiting approval and a growing number of people (including us) build their own closed-loop systems.

Insulin pumps cost $2500-$6000 on average and then there are ongoing supply costs. The most common continuous glucose monitor, Dexcom, costs at least $8,000 a year without insurance. The cost for one month of supplies is over $500. While these are expensive, there is a return on that investment. An ER visit to stabilize blood sugar for someone with diabetic ketoacidosis is over $10,000 and that is without a hospital admission (information from our endocrinology practice). People are better able to manage their disease with the support of this equipment.

People living with diabetes also have costs associated with emergency supplies. Glucagon is an emergency treatment for persistent low blood sugars. It works by signaling the liver to release glucose stored there. It costs upwards of $200. Like EpiPens, this is an emergency supply you hope you never need to use. Insurance sometimes covers glucagon and other times it does not. Sometimes it covers only and older version that requires mixing rather than a newer version that is an inhaler and is delivered similar to Narcan. It is much easier for the user. During the last general assembly, the legislature allowed schools and camps to stock glucagon for emergency use as they do EpiPens but they have not yet adopted policies and begun doing this.

As you are probably already aware, CMH helps many families afford insulin and supplies to safely manage diabetes. Our family is fortunate that we have been able to plan and budget for these costs. So many of us, though, worry about what happens when our children become young adults. Will they have good insurance? Over 40% of Americans have high deductible insurance and that percentage is growing as employers seek to limit increases in health care costs. We had high deductible insurance for 17 years. Until my son's diagnosis, we rarely met our deductible. The first quarter of the year brings huge bills the first time you place an order for supplies. Thousands of dollars for insulin. Thousands for the continuous glucose monitor, hundreds for test strips. Over a thousand for pump supplies. We worry that our children won't have good enough coverage or good enough jobs to cover this cost as they get established. We worry about when we can retire just from a healthcare perspective. Allowing young people to remain on CMH would help them transition to adulthood. It would be an investment in their health, helping them to better manage their disease and stay health as they get established as independent adults. I encourage you to support HB 212.

Thank you,

Cassandra Freeland
110 Brevoort Rd.
Columbus, OH 43214
614-707-6429