Submission

Stage 2 of Diabetes Products Review - Insulin Pump Program

Background

My daughter, Izzy*, is 8 years old and was diagnosed with diabetes when she was 5 years old. Her diabetes was controlled well on insulin injections for 18 months, before becoming unstable. Injections were increased to three times a day, with a view to four times a day. Despite all efforts, Izzy continued to experience the full spectrum of blood glucose levels (BGLs) most days, from very low (1.7mmol/L) to very high (28mmol/L). Consequently, her health deteriorated. She felt constantly tired, moody and unwell, as the unstable blood glucose levels knocked her body about and made her vulnerable to viruses and other illnesses. In addition, the injections had become a traumatic experience which she had to endure three times a day. In her mind, it wasn't worth the pain and trauma if it wasn't doing anything to help her feel better. As a result, we looked at insulin pump therapy as an alternative.

The Insulin Pump

Izzy was issued with a Medtronic insulin pump in September 2012, which was made possible with the full 80% subsidy through the JDRF Insulin Pump Program. We undertook education at Monash Medical Centre at the Diabetes Ambulatory Care Service (DACS), of whom I cannot speak too highly.

The insulin pump works in a similar way to a normal functioning pancreas, only it is manually operated. There is background insulin, called basal insulin, which is delivered continuously. Extra insulin is administered when carbohydrates are consumed. This is called a bolus, and is achieved by entering a BGL (if appropriate) and the quantity of carbohydrates. As such, flexibility in her eating routine entered Izzy's life for the first time in two years.

Within a few days of commencing, Izzy got her "oomph" back. Her enthusiasm and zest for life reappeared. We got our "old" Izzy back. Her BGLs were less erratic.

How life has changed since having Insulin Pump Therapy

- *Greater stability of BGLs* – Izzy experiences less extreme blood glucose levels (Izzy's first HbA1c post pump therapy will be in late February 2013, so we have no data available as yet to verify that her diabetes control has improved).
- *Long term risks reduced* – Better diabetes control means that the risks of Izzy getting diabetes complications (such as diabetic retinopathy, diabetic nephropathy, etc) have decreased.
- *Greater independence* – with guidance and support from an adult (eg. with carbohydrate counting, reminding to do BGLs), Izzy has been able to become more independent. She feels greater confidence at playdates and the pump has facilitated her first sleepover recently.
- *Normality* – Izzy has been able to regain, to some degree, the normality that her peers experience, through the increased ability to be spontaneous in relation to activities and food.
- *Greater control over her own diabetes* – previously the diabetes controlled her life. On injections, Izzy was required to eat at specified times of the day and eat a specified quantity of carbohydrates (no more and no less). On pump therapy, the routine is more flexible and Izzy has been empowered by being able to decide how much SHE wants to eat and is able to fit in more with changes in eating routines.
- *Increased energy* – her energy levels are more on par with her peers now than before pump therapy. There was a noticeable change within a few days of commencing pump therapy.
- *Feels better overall* – and, as a consequence, has had less illness since having insulin pump therapy.
- *Easier diabetes management during illness* – with the flexible eating routine, if Izzy doesn't want to eat because she feels too sick, she doesn't have to. On injections, even with reduced insulin, Izzy was still restricted with eating a certain amount of carbohydrates at a certain time of day, so still had to eat during illness whether she felt like it or not.
- *More manageable growth spurts* – owing to the flexibility with eating, growth spurts can easily be accommodated for on pump therapy. There was always a delay and an adjustment period of at least one week to accommodate for growth spurts while on injections.
- *High BGLs don't have to be endured* – high BGLs can be promptly corrected using the Correctional Bolus function on the pump, thus bringing the BGL down to target level within 2 hours. On injections, there was little that could be done except to "ride it out" until the BGL came down by itself. Thus, the amount of time that Izzy experiences the symptoms of hyperglycaemia (hunger, thirst, increased urination,

moodiness, hyperactivity, lack of concentration, shakiness, lethargy) has decreased, allowing her to feel better sooner if she does have hyperglycaemia.

- *Less injections* – Izzy has to endure an "injection" only once every three days (with the cannula insertion) as opposed to the three to four times a day when using syringes. The insertion of the cannula is far less traumatic for her than the injections.
- *A big commitment for injections* – if Izzy had not commenced insulin pump therapy, her insulin regime would have increased to four insulin injections a day. This would have included one at lunchtime, and would have required me to attend her school before lunch every school day in order to give her the injection, until she could inject herself (normally about the age of 10). Needless to say, this has been a huge relief to not have to go down this path.

The importance of the JDRF Insulin Pump Program subsidy

I was fortunate to qualify for the maximum subsidy offered by the Insulin Pump Program. The subsidy paid for $6,400 of the $8,000 pump. This subsidy enabled Izzy to access insulin pump therapy, which offered the hope of better diabetes control and therefore better health. My stress levels were enormous caring for a child with unstable diabetes, so it was a huge relief to have the financial burden of life-improving treatment lifted off my shoulders. My financial situation wouldn't have allowed me to purchase the pump, as I am a single parent relying on Centrelink for my income. Health insurance payments stretch beyond my budget. I investigated health insurance for Izzy, but the health insurers do not offer health insurance for a child only. This made it financially difficult if I were to pay for family health insurance.

Summary

In summary, the Insulin Pump Program was vital to our family accessing insulin pump therapy, which has changed all of our lives for the better. It has enabled better control of Izzy's diabetes, better health, greater independence, greater flexibility, and reduced trauma associated with injections. The long term benefits include a reduction in the risks of diabetes complications. I urge you to continue the Insulin Pump Program to enable other families to experience the benefits of insulin pump therapy.

* name has been changed.