

CHILD HEALTH



Family gives thumbs up to pumping

At the start of their year-long stay in Ireland the Lerner family from Ohio spoke to **Sheila O'Kelly** about how two of their children who have type 1 diabetes use insulin pumps

Michelle and Mitch Lerner from Ohio have three children, Camille (12), Julia (8) and Max (4). Julia and Max have type 1 diabetes and both of them use an insulin pump. Mitch is a professor of the History of American Foreign Policy at Ohio State University and is on a year-long secondment to University College Dublin's history department as Distinguished Fulbright Chair.

Julia was diagnosed with type 1 diabetes just before she turned five

and Max when he was 22 months old.

"In fact Julia was diagnosed September 11, 2001, and when we came out of the hospital we had no idea what people were talking about," said Michelle.

When they went home that morning there were 25 messages. "They were all people saying 'are you watching TV?'" and we turned it on just in time to see the second tower collapse," said Mitch. "It was just overwhelming. Whenever I get

depressed about diabetes, I think well we got home from hospital that day – a lot of people did not come home at all."

Max's diagnosis on Thanksgiving was equally traumatic.

"It was awful," said Michelle. "Dinner was literally being taken out of the oven and we just left it all over the kitchen."

The Lerner family had just put in their order for Julia's pump when Max was diagnosed.

"With the pump it's a whole different lifestyle," said Mitch. "Everything changes. I know many Irish parents have had a harder time than we did getting their children on pumps, but I could not stress enough that it's worth fighting for.

"It takes six months to get it right but within a week of pumping, we were better off than when we were using shots. At the end of six months Julia's A1c was 4.8 without going too low very often, she felt much better and we all had an easier life," said Mitch.

Michelle said they had more flexibility as a family. "Not just for Julia but all of us. Most families are not able to live to a rigid timetable. There are things like soccer, or here you have hurling, and the pumps allow us to fit those kinds of things in."

In Ohio the family used to go out to dinner every Friday and there would always be a debate about whether Julia and Max would have another injection so they could have an ice-cream.

"We'd be carrying around the needles," said Mitch "and they'd always choose to have another shot but it was never any fun for anybody."

Now they can eat whenever it suits. "It's just a matter of pressing a few buttons on the pump – easy as can be," said Mitch.

Insertion site

The insertion site for the pump needs to be changed every two-three days. Julia has got used to this process and they no longer need to use the anaesthetic cream, although the Lerner's still use the "magic cream" for Max.

"Julia doesn't even feel it," said Mitch. "We do site changes in the middle of the night sometimes and she doesn't even twitch. It does tend

Eight-year-old Julia – in her own words

Julia was six years old when she started using an insulin pump and she wears it in a pouch on her belly.

Do you remember what it was like before you used a pump?

"Yes, I didn't like it".

Why do you prefer the pump?

"You don't have to take shots all that often and you can push a few buttons and the parents don't have to go through all the hassle of loading the insulin into the needle."

Julia does have to test more often now that she uses the pump and most of the time she tests herself – about 10 times a day.

Is there anything else you prefer about the pump?

"I like the colour...and I can eat what ever I want." Julia likes that this makes it easier for everyone.

"I can go on sleepovers, before Mommy always had to stay with me. I can go to birthday parties," said Julia who said they were more fun to enjoy now.

Do people still have lots of candy at birthday parties?

"Yes they always have lots of junk food. Pretzels, and most of the times there's cake."

"And Julia can eat whenever, not just what ever," said her mother Michelle. "Or not – Julia doesn't have to eat if she's not hungry."

Julia have you met many other children with diabetes?

"My mom and dad usually invite people for dinner if they have a child who is new to diabetes."

"Can I tell you about what happened last night?" asked Julia. "Well I woke up at 1.30 in the morning and went to the bathroom and after that I tore out my site. So when I'd done in the bathroom I went into their room and I told my mom. I went back to bed and a few minutes later she came in and did a site change."

Michelle adds that Julia didn't really even notice when the change was being done.

to fall out at things like swim lessons so we probably average changing it every two days.

Calculating the dosage

"The more recent versions of the pumps will pretty much solve the calculation for you," said Mitch. "You have to count how many grams of carbohydrate they eat, then you enter that into the pump's computer and it will tell you how much insulin they should get.

"You are still the one responsible for doing those settings," said Mitch. "So it's a real practice and error – it took us six months before we really had their settings right. I still adjust their rates and settings now and again. They're growing and their hormones are changing, but once you get it set right it's the easiest thing in the world."

US diabetes training

"In our state," said Mitch, "it's

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generally a five-day training course in the hospital when you're diagnosed with diabetes. When you start pumping for a follow up that's 24-48 hours of monitoring."

"Our doctor has a three-session seminar you have to take before you can start a pump. It's a total of eight or nine hours. One where they show all the different pump choices and then another where you learn about counting carbohydrates and that type of thing," said Michelle.

Parents can programme the pump to sound an alarm when the insulin is running low and this can be set at whatever level the parents choose. The Deltec Cosmo (Smiths Medical) pumps the Lerner's use hold 300 units of insulin.

Insulin units

"At breakfast they might get a whole unit of insulin for each 15 grams of carbohydrate," said Michelle. "Whereas at lunchtime they might only get a half a unit of insulin for each 15 grams. It's very nice, very easy. It's really perfect for children."

The Lerner's said the pumps were also much better for avoiding hypos at night time.

"That's another thing about children – you can't measure a small enough amount of insulin by eye in a syringe. The pump can give down to a twentieth of a unit as a bolus for food and you can give even a smaller amount as a basal," said Michelle.

Mitch pointed out that the pumps also left less room for human error. "You try to measure six units of Lantus or eight units, but maybe you get 8.2. And with a fast insulin like Humalog or Novolog you try and give six units and you give 6.2 – well that .2 is going to make a huge difference to someone like Max."

Michelle said that .2 is a typical amount they would give Max when

'Basal' and 'bolus' insulin

Basal insulin

This is the insulin delivered by the pump every few minutes right throughout the day.

Bolus insulin

This is the extra insulin you get the pump to deliver when you eat carbs.

he is going to eat a cookie.

"So the pump gives him exactly what he needs. At night Max's basal rate is so low he gets .1 units of insulin every hour over the night," said Mitch. And it shows. Julia's last A1c was 5.8 and Max's was 6.6 – for kids that young that's really good – and they very rarely have hypos."

Hypos

Michelle said they can still get the occasional hypo and they are usually caused by something like swimming or other exercise.

"Max is more prone to hypos than Julia," said Michelle. "That's because he's not a great eater – or sometimes we miscalculate."

But generally the pump has made an even bigger difference to Max's health than it has to Julia's.

"It's so horrible with a picky toddler," said Michelle. "There were times before Max had a pump when I would be crying sitting on the kitchen floor because he had to eat and he wouldn't. It was awful – very hard to control. With a two-year-old you can't tell them, 'you've got to eat this now'. And he can't tell us 'I feel low now'. You never know what he's going to eat, when he's going to eat, how much he's going to eat."

"And the shots – not that Julia ever loved the shots – but Max was two years old, he didn't understand

he had to have a shot. He just saw the needle coming out and he would start to cry. It was terrible. So now he's just like Julia he barely feels the site changes. He's happily running around – it makes life so much easier for the younger kids," says Michelle.

Consultant resistance

Max started using the pump six months after he was diagnosed when he was just two and a half years old. The Lerner's say their doctor probably took into account that they were doing such a good job with Julia when he helped them to start with Max's pump. "He knew we knew what we were doing," said Mitch.

The Lerner's said that more and more parents in the US were switching their children to insulin pumps.

"Even five years ago we encountered some resistance from our initial endocrinologist who didn't really love the idea of pumps. We switched endocrinologist. Now in the US it's reached a point where everyone is either on the pump or thinking about pumping."

The Lerner's are very active in a local support group in Ohio for families where someone is using a pump.

School lunches

"At home in Ohio," said Michelle, "we always pack lunch. Here school is set up a little bit differently and they serve a very nice lunch and the kids want to eat that. We're going to have to rely on the teacher a little bit more for looking at portions and stuff like that."

"In Dublin, we chose the John Scottus school because everything we looked at there really impressed us. They were also good about the diabetes. But the decision was made for all kinds of reasons," said Michelle.