



# The Bergs:

## A Family Science Project

By Rob Dinsmoor

**I**f you have diabetes, you know how hard it is to constantly keep track of your blood sugar levels, your insulin doses, and your diabetes supplies. Now imagine what it would be like to have two people in your family with diabetes. That's exactly the case with the Berg Family. Having two kids with diabetes has been a real challenge, but it has also made the Bergs extremely valuable to a diabetes research project that explores the genes involved in causing diabetes. And the whole family was willing to step up to the plate.

### Diabetes Diagnosis Times Two

Toni and Rob Berg, who live near Seattle, Washington, have three kids—Heather, 11, Dillon, 8, and Aiden, 5. Aiden was diagnosed with diabetes a few months after his first birthday. Everyone thought he was sick from an ear infection,

but after it went on for a long time, Toni insisted that it was something more. No one expected to see diabetes in such a young child, but when the doctor tested Aiden's blood sugar, it was sky high.

One day, less than two years later, Toni and Heather, then 9, received free glucose testing at Costco. It turned out that Heather's blood glucose was very high. At first, Toni thought the high reading was just a fluke. She didn't want to believe that another one of her children had diabetes—but the doctor tested Heather's blood sugar a couple days later and it was still high.

"When Heather was first diagnosed, I was in such denial. I said, 'No way. It's something else,' I just couldn't accept it!" Toni recalls. "But Heather said, 'Mommy, you know what? If I have diabetes, it's okay because I can handle it.' I thought if she was brave enough to handle it, then I could be brave enough to handle it."

For Toni and Rob, managing two kids with diabetes was very tricky. There were two syringes, two different types

## Role Model



of insulin, and two different doses. What if they mixed up the syringes? To their shock, that's exactly what happened!

"It was awful. It was the worst night," Toni recalls. "Heather's dose of NPH was much higher than Aiden's at that time, so we had to wake up Aiden every two hours and make him drink juice to keep his blood sugars up to where they should have been. I remember thinking I could never let that happen again."

## Taking Charge

Then Heather made things a whole lot easier. "She stepped right up to the plate and said, 'Mommy, I can do this and this and this.' She was checking her own blood sugars from that day on, and she would check my insulin draws and say, 'This one's Aiden's and this one's mine,' just to make sure, because she knew how freaked out I was," Toni recalls.

"When I was diagnosed, Aiden already had diabetes. I think it was easier for me because I already knew how to check my blood sugars and stuff," says Heather.

The danger of syringe mixups was no longer an issue after Heather pressed her parents to let her go on an insulin pump. At first, they had a hard time getting the basal rate just right. "But then Heather said, 'I'll do whatever I need to do to be on the pump,' because she hated the injections," says Toni.

"I found it's a lot easier to be on the pump," Heather says. "I don't have to eat at a particular time. I can eat whenever I want. I just have to keep track of my carbs and not pig out!"

All three of the Berg children are active in sports all year round, and that seems to help Heather and Aiden control their blood sugars. "They're constantly active in the summer anyway," says Rob. "We put up the pool and they're outside riding bikes. We notice it makes a big difference in their blood sugar numbers. They're more active and they're also not sitting around and eating constantly."

## Volunteering for Science

Even before Heather was diagnosed, Toni and Rob couldn't understand how Aiden could have developed diabetes as



For more information about clinical research trials, go to [www.jdrf.org/clinicaltrials](http://www.jdrf.org/clinicaltrials).

neither parent has a history of diabetes in the family. (As they later found out, 9 out of every 10 kids who is diagnosed with diabetes doesn't have any diabetes in the family prior.) Naturally, they also wanted to know whether Dillon, too, was likely to develop diabetes. They contacted researchers who were studying the genetics of diabetes and how the risk of diabetes is passed on from parents to children. After Heather was diagnosed with diabetes, the Bergs became an ideal "sib-pair" family for the International Type 1 Diabetes Genetics Consortium.

The Consortium is exploring the genes of thousands of families worldwide to see if it can identify genes that raise or lower the risk of getting diabetes. What makes the Bergs especially valuable to the Consortium is that they are a "sib-pair" family where at least two siblings (brothers and sisters) have type 1 diabetes. Even more valuable is that their brother, Dillon, does not have diabetes. By studying two siblings with diabetes, researchers



## VITAL STATS

**Ages:** Rob, 39; Toni, 38; Heather, 11; Dillon, 8; Aiden, 5  
**Home:** Renton, Washington  
**Sports:** Gymnastics, basketball, swimming, cheerleading (Heather); soccer, baseball, swimming (Dillon); baseball, gymnastics, swimming (Aiden)  
**Favorite vacation destination:** Disneyland

blood, they kind of shied away from it, especially Dillon, but he finally said, "Yeah, I'll do it, Mommy."

"We like to be involved because we understand there aren't a whole lot of families with sibling pairs who are willing to enroll in this research," says Rob. "I understand the benefit of being able to see the similarities of the diabetic children and how they differ from the child without diabetes. It's a huge benefit."

The most nerve-wracking part of it all was waiting for Dillon's blood sample to be analyzed. Was he likely to become diabetic, like his brother and sister? After weeks of nervous waiting, the results came back:

Dillon was not at high risk for diabetes!

Toni has been trying to recruit other families to volunteer for diabetes research studies. "I wish more families would participate in research. I've talked with a couple of families where some kids have diabetes and some kids don't. They haven't participated because they've never been informed of these studies. So, I tell them about it and urge them to talk with their doctors about it," she says.

For Toni, one of the best parts of participating in research is getting information from the researchers. "They always give us new information. They let us know what studies are coming up and where the research has gone," she says. ●

can take note of what genes they have in common, which might turn out to raise or lower the risk of diabetes. The Consortium still does not have enough "sib-pair" families to reach its goal of 1,200 families.

Scientists already know some genes that clearly raise the risk of diabetes, and they can use genetic blood tests to predict how likely someone is to develop diabetes. "I jumped at the opportunity to participate," Toni says. "When I told the kids that the test involved drawing