



SPOTLIGHT

## Diabetes never takes a vacation



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Six-year-old Sophia Honig knows what she likes — the color purple (pink, green and black have all had their share of attention), PB&J sandwiches, playdates with friends, swimming, horseback riding, reading, drawing and playing dress-up.

And what she doesn't like — shots (seven a day) and the frequent changing out of the needle of an insulin pump she wears round-

the-clock to deliver insulin on demand.

She is only just coming to grips with having her finger pricked 10 times a day and twice at night to check her blood glucose levels.

The St. Helena Primary School first-grader was diagnosed with Type 1 diabetes a year ago.

This summer from July 8 to 10, she and four other Bay Area youngsters will be joining the 2013 Children's Congress — 150 young delegates ages 4 to 17 from 50 states and the District of Columbia, all with Type 1 diabetes. They will be in Washington, D.C., with their families to petition Congress for diabetes research funding. They also plan to meet with senators and representatives.

The number of diabetics in the U.S. is estimated at 25.8 million. Most have the more common Type 2, which occurs when the body becomes resistant to the effects of insulin or doesn't produce enough of it.

Ten percent (about 3 million people, mostly children and adolescents) have Type 1, once known as juvenile diabetes. Type 1 is a chronic condition — the pancreas produces little or no insulin, a hormone needed to allow sugar to enter cells to produce energy. Although there is no cure, it can be managed.

"Type 1 never takes a vacation," said Sophia's father, Michael Honig. "Type 1 means ... sufferers require regular injections of insulin to control and regulate the body's metabolism. Unlike those with Type 2, Sophia can't manage diabetes by monitoring her diet or using exercise to maintain her health."

One recent afternoon after the family's return from an end-of-school field trip, Sophia's father checked his daughter's sugar levels as her younger brother and sister talked excitedly about the trip. Following a prick of her finger, a read-out on a blood glucose

meter showed her levels at a “perfect” 126. Earlier in the day it had been a low 55, which required an immediate sugar boost.

“I had apple juice and a quarter of a (fig) bar,” Sophia explained. “Apple juice will get me right up.”

When a child is diagnosed with Type 1, it involves the whole family, her father added. Sophia can eat anything she wants, but everything she eats has to be evaluated for its carbohydrate content. Carbs hike up the blood sugar levels, and insulin has to be administered to keep those levels in a healthy range.

“Pizza and ice cream are probably the two most complicated foods to give insulin for,” said her mother, Stephanie Honig. “When you have a combination of fast-acting carbs and slow-acting carbs, it gets complicated. You learn through trial and error.”

If Sophia keeps her sugar levels in check and remains healthy, “she can have a long and active life,” her father said, “but if we don’t keep the levels up, there can be problems with circulation and vision. If sugars are too low, the body can go into shock. That’s why there is so much angst as a parent; you have to keep the levels just right.”

It’s an understatement to say that last year’s diagnosis took Sophia’s parents by surprise.

“Diabetes wasn’t on our radar at all,” her mother recalled. “I just thought she was going through a bad phase. She was tired, didn’t want to play or eat, and she was drinking a lot of water, but it was June. She started losing weight.”

It was her pediatrician, Dr. Ralph Myers, who picked up on it. “We were completely shocked,” Stephanie Honig said. “We had no idea.”

Sophia was admitted to St. Helena Hospital, then to Oakland’s Children’s Hospital and eventually to UCSF Medical Center.

The parents joined support groups in Marin and Napa, connections they say have helped in many ways, both practical and emotional.

Last summer the whole family, including 4-year-old Lola and 2-year-old Sebastian, attended a camp in Sequoia National Park run by the Diabetic Youth Foundation.

“We were full-on trying to figure things out,” Sophia’s father said. There were 50 families at the camp, and while counselors oversaw activities for the children, the parents were in classes getting a crash course on Type 1 diabetes.

Everyone benefited, he added. The parents were learning what they needed to know about managing diabetes, and Sophia could see that the counselors — 18- to 24-year-olds, all with diabetes — were athletic and healthy.

When it came time for Sophia to enter kindergarten, her mother contacted the insulin pump company and arranged for a representative to visit Sophia’s class at St. Helena Primary School.

“He sat with them in a circle and talked about what diabetes is,” she said. “He has a pump, too. The kids were great with their questions ... and they are all used to it now.”

“The school has been amazing,” she said later, singing the praises of the district’s Assistant Superintendent Cindy Toews and school Principal Tom Hoskins, as well as Sophia’s teacher, Nichole Landis, and paraeducator Amber Long, who checks Sophia’s insulin levels and ensures she gets the dosage she needs. “I tell Amber she’s a guardian angel,” Stephanie Honig said. “She cares, and Sophia loves her. When she’s at school I don’t worry. We are so lucky to have a public school like that. I can’t say enough.”

Sophia may have diabetes, but it isn’t slowing her down. She takes riding lessons in Oakville — Smokey is a favorite horse — and she enjoys tooling around the family vineyard on a child-sized dune buggy.

When she goes to a friend’s house to play, the parents will text her glucose levels to her mother, who can text back what to do. “If she’s in range,” her mother said, “I have piece of mind, and she can play.”

Sophia is looking forward to her upcoming trip to Washington, D.C. Her wish is to meet President Barack Obama and have her picture taken with him.

“She’s a little trouper ... and she really tries,” said her father, “but she has this terrible thing she doesn’t understand. When I’m changing the needle, she’ll look at me with tears in her eyes and ask me, ‘Daddy, why do I have to have diabetes?’”

Before Sophia was diagnosed, she wanted to be a princess. “Now,” he said, “she wants to be a doctor to find a cure for diabetes.

“She is a child with diabetes, but diabetes is not what she is. We really want her to have a full life.”