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Bag of Hope: A Mother's Story

By Jo Eager

It was 5 p.m. on a Friday when Nathan came to the door, a smile lighting his face.

It was Nathan's eighth birthday, but this blond, blueeyed stranger was the one bringing gifts: help and hope for me and my 6-year-old son, newly diagnosed with diabetes.

Fear and Answers

For several months, my son Kaipo had been struggling with bedwetting, frequent nighttime trips to the bathroom, and excessive thirst — obvious red flags in hindsight, but symptoms I then chalked up to a phase.

Then, in testing Kaipo for a urinary tract infection, his pediatrician found high blood sugar. Two weeks later, we were at a specialist's office. Within an hour of that appointment, Kaipo was admitted to the hospital.

Later, I would learn that we'd been fortunate: Because Type 1 diabetes (once known as *juvenile diabetes*) often progresses silently, some children are not diagnosed until they arrive at an Emergency Room in a coma.

At the time, however, I felt anything but lucky. Among the calls I made in those panicked first days was one to the Juvenile Diabetes Research Foundation.

Now, Nathan had arrived to answer that call.

Rufus

With Nathan were his parents and younger brother. On his shoulder, he carried something called a "Bag of Hope."

Kaipo greeted them at the door.

"Show Kaipo what's in the Bag of Hope," said Nathan's father.

The boy spilled the bag onto the couch. Rather than save the best for last, he started with it: a teddy bear named Rufus.

"I sleep with mine every night," Nathan told Kaipo.

Rufus, the Bear with Diabetes™, comes with a medical identification bracelet to show that he has diabetes. He also has patches on his arms, legs, abdomen and buttocks to show where he takes insulin shots.

"I give Rufus shots, just like I have to take," said Nathan.

He then went through the rest of the items, giving some to Kaipo and some to me. There were kids' books, coloring books, a video, and some literature for parents.

Finally, Nathan took out his blood testing kit and showed Kaipo how he tested blood from his arm instead of his



Kaipo, the author's son, has found a friend in Rufus, the Bear with Diabetes



fingertips.

Connections

Nathan's father had called earlier that day to set up a time to meet. Nathan had been diagnosed with diabetes six months before, his father said.

"When was your son diagnosed?" he asked.

"Two weeks ago."

"You must be a basket case."

He understood. Here was someone who could relate to me in a way that others couldn't.

"Yes." I told him. "Sometimes I just start crying in the middle of a conversation."

He knew the fear I felt, the grief, the sadness, the loss.

Nurse Mom

It was amazing how much life had changed overnight. One day, I was juggling laundry and homework. The next day — and all the ones that would follow — I was a nurse: checking my son's blood at least four times, giving him insulin shot twice, making sure he ate the right amount of food six times.

When I dropped him off at school, my worries were so magnified from just days before: Would he know if his blood sugar was too low? I recited the symptoms over and over to him.

Our three-day stay in the hospital had been intense. It was a crash course in diabetes, and it was overwhelming. I knew that once we got home, I wouldn't have nurses there to answer my questions. I was on my own.

Single Parent, Double Stress

What if I forgot something crucial from those frantic lessons? I didn't have another parent in the home to help me remember all the instructions, terms and warnings that had poured into my brain. My worry was constant and extreme.

That's the part of single parenting that I find hardest: taking on 100 percent of the fear and stress of the situation.

Nathan's mother said she had worried about her son's blood sugar level getting too high. His dad worried more about it dropping too low.

I worried about both but was more scared of hypoglycemia (low blood sugar). It happens quickly and can lead to unconsciousness. If it plummeted in his sleep, would he wake up?

Feeling Normal

But now, parents like Nathan's let me know that my fears were normal. When they invited me to call, I knew they meant it. I could tell them anything, and they would understand.

"It was bedtime and his reading was low. I gave him extra carbohydrates and had him sleep in my bed."

"We've all done that."

Most parents say it takes a year to feel comfortable with their child's diabetes. "I cried every day for three months after my child was diagnosed," the woman at JDRF said when I called.

Bear Necessities

Nathan's "Bag of Hope" brought more than coloring books and information. With it came experience, kindness and empathy.

And Nathan's parents were out offering support to others just six months after their son's diagnosis. That gave me a lot of hope. My tears, I thought, would dry in their own time.

Tips for Parents

If your child has diabetes, [click here](#) for some Mom-to-Mom hints the experts may forget to share with you.

Learn More!

If your child has diabetes, don't go it alone. Among the best resources:

- Pediatric Education for Diabetes in Schools (PEDS): www.pedsonline.org
- Children with Diabetes: www.childrenwithdiabetes.com
- Diabetes Living: www.diabetesliving.com
- Barbara Davis Center for Childhood Diabetes: www.barbaradaviscenter.org
- Juvenile Diabetes Research Foundation International: www.jdrf.org
- American Diabetes Association: www.diabetes.org

That evening, after I gave Kaipō his shot of insulin, he took the used syringe and gave Rufus a shot. As a matter of fact, Rufus had several shots that night.

It must have been the right dose; Rufus slept peacefully in Kaipō's arms all night.

The dose of hope we all received that day was just right, too. Like Nathan, Kaipō has been holding his bear tight every night.

If it's true that in giving we receive, Nathan had the best birthday ever.

Jo Eager is a freelance writer and broadcast journalist in San Diego, Calif. Her articles have appeared in numerous publications, including USA Today, the San Francisco Examiner and the Indianapolis Star.

Tips for Parents

- **Keep moving.** Many parents become so focused on their child's diet and medication that they forget about exercise. But physical activity is crucial. It increases insulin sensitivity. That allows the insulin to work more efficiently, usually requiring a lower dosage.
- **Fuel for short-term activities:** Milk, juice and other liquids are absorbed most rapidly and can help prevent low blood sugar for 30 to 60 minutes.
- **Fuel for longer activities:** Solid foods are digested more slowly than liquids and usually provide protection for two to three hours. Include fat and protein with a carbohydrate.
- **If low blood sugar occurs during exercise** have the child rest for at least 10 minutes after treating him or her.
- **Always carry a fastacting source of sugar,** as well as a longerlasting snack.
- **Be cautious about exercise** when the urine ketone level is large or moderate. Activity may increase the blood sugar or ketone level.
- **Think about the best place for an injection** before exercise. For example, if your child is about to play soccer, it's best to choose an injection site other than the leg.