Be A Hero!

HELP PREVENT DIABETES WITH THE GREAT KATIE KATE

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with illustrations by Jennifer Zivoin
Claire sat on the hard chair in the doctor’s office. She was tired and bored. She wanted to play outside. Instead she was stuck waiting for her brother—again. Ever since Andrew found out he had type 1 diabetes a month ago, it was the same thing. Claire was dragged along to every single one of Andrew’s doctor appointments.

*No one pays any attention to me anymore, Claire thought.*

*Why do I have to be here?*
One day the doctor said that she needed to see Claire, instead of Andrew. *How weird!* thought Claire. *I don’t have diabetes. Why would she want to talk to me?*

“How would you like to do something really fun?” Andrew’s doctor asked Claire.

“How, me?” Claire said.

“Yes, you,” said the doctor, smiling. “Do you like to swim and play games?”

“Always!” Claire answered.

The doctor told Claire about a special summer day camp for children who have diabetes and their brothers and sisters. Claire and Andrew could go together, she said. They would play games, make crafts, and meet lots of new friends. They would also learn more about diabetes.

“How can we go?” Claire asked Mom and Dad.

Mom and Dad agreed that camp sounded like a great idea.
The first day of diabetes camp arrived. Claire and Andrew had so much fun! Andrew met all kinds of kids who also had diabetes. They had to take insulin and count their carbs, just like him.

Claire made new friends, too. Many of them had brothers and sisters who had diabetes, just like Andrew. Claire found out that they did not like waiting in the doctor’s office either.

All of the kids had a swimming race, and then they ate hamburgers for lunch. Everyone was excited to be at summer camp!
The next day at camp was a special parents’ day. All the parents were invited to spend the day at camp with their children. Claire and Andrew were excited to take Mom and Dad around the camp and show them all the things they had done and made.

They were walking to the swimming pool when suddenly Claire felt a tap-tap-tap on her shoulder. She turned around and there was a girl she’d never seen before. The girl had red hair and wore a long purple cape.
“Are you a camper?” asked Claire.

“Sort of,” said the red-headed girl. “I’m The Great Katie Kate!” She wiggled her nose, which was covered in freckles, and then looked side to side to see if anyone was watching.

Katie Kate leaned in close and whispered, “You’re Claire, right?” Claire nodded.

“I have something really special to show you. Come with me!”
Claire followed The Great Katie Kate and her purple cape outside. There was a tent there with a big banner that said “TrialNet” over the entrance.

“You’re going to hear about something really amazing,” said Katie Kate. “Find your mom and dad and talk to the scientist inside this tent. He’ll explain a very special mission that you can help with.”

“What kind of mission? And what’s TrialNet?” asked Claire.

“Go get your mom and dad and you’ll find out! It’s for kids like you who have a family member who has diabetes.”
Inside the tent, Claire saw many of her new friends with their parents. All of the kids had a brother or a sister who had diabetes. A man in the front smiled at the group and waved to them to sit down.

“Welcome!” said the man. “I am a scientist with TrialNet. You’re probably wondering what TrialNet is.” Claire and the others nodded.

“Well, TrialNet is a group of people who are working very hard to learn more about diabetes and to find out how we can keep kids from getting it. And guess what? Because you are the brothers and sisters of kids who have diabetes, you can help us on a very special mission. Believe it or not, you can even be the heroes on this mission.”
Type 1 Diabetes
A special hero’s mission. How exciting! thought Claire. She looked at Mom and Dad. They were all ears too.

The scientist continued. “You can do something to help us find answers about diabetes. Do you want to know what that something special is?”

“Yes!” all the children in the crowd yelled.

“Well, if it is okay with your parents, you can let us do a test here at camp. When we do the test, we take a small amount of blood from your arm. It is a very easy to do. Scientists like me will study your blood. What we find will help us learn about ways to keep kids from getting diabetes.

“Believe it or not, that’s all there is to it. Just think: maybe one day kids like your brothers and sisters won’t have to give themselves shots or have an insulin pump or check their blood sugar every day. Wouldn’t that be great? That sounds like being a hero to me.”
Claire listened carefully to the scientist. She liked the idea of helping Andrew and other kids with diabetes. She thought it would be really neat to help keep other kids from getting diabetes.
But Claire suddenly felt a little funny in her tummy. She was worried. She had a lot of questions about the test.

And just like that, she heard a psssst from behind the rows of chairs in the tent.

“Hey, Claire! Over here!” called The Great Katie Kate. “I know you’re wondering about the test. I can show you how it works. It really is easy, and if you do it you can be the hero of the mission!”
“I want to do something to help other kids,” said Claire. “But does the blood test hurt?”

“Some kids say that it feels like a little poke, and it’s over really fast,” said Katie Kate. “If you decide to help us, how about you tell me what it feels like to you?”

Claire liked Katie Kate’s answer.

Claire still had questions for Katie Kate.

“If I help,” asked Claire, “will Andrew not have diabetes anymore?”

“Unfortunately, no,” said Katie Kate. “But you will be helping us find ways to keep other kids from ever getting diabetes. You’ll be a hero to so many people you don’t even know.”

“You’re kind of a hero, Katie Kate,” said Claire.

“Well, sort of,” said The Great Katie Kate. “Heroes are brave and do amazing things to help other people. Brothers and sisters of kids who have diabetes have a chance to be true heroes!”

Claire was excited about being a hero. “What happens after I take the test?” she asked. “Will I have to go to the doctor a lot, like Andrew does?”

“Well, most kids are asked to help TrialNet with a blood test once a year. But if the scientists find something special in your blood, they might ask you to be a hero again soon. They’ll let you know what your next mission might be.”

Katie Kate smiled, and Claire smiled back.

Talking about it was making her tummy feel better.
Claire thought about the day Andrew found out he had diabetes. She thought about how worried her parents had been. She thought about how Andrew had to go to the doctor all the time, how he had to give himself shots and check his blood. She remembered when he had to learn how to use his insulin pump. And how he had to keep track of how he was feeling and what he ate. Claire could not do anything to change all of that for Andrew, but if she helped the TrialNet scientist with his mission, she could make a difference for other kids. She could be a hero!

“Mom, Dad!” she called. “I want to be a hero. Can I do the blood test?” She gave a big thumbs-up.
Soon it was Claire’s turn to get her blood test. A nurse was going to do the test.

Claire felt a little nervous inside. Andrew stood by Claire’s side to help her feel safe while the nurse rubbed a special magic numbing cream on her arm.
“This cream makes it so you don’t feel the poke as much,” the nurse said. “You’re doing a great job. Just keep sitting still and we’ll be done before you know it.”

“I’ve had a lot of blood tests, Claire,” Andrew said. “I know you can do it! How about we sing a song we learned at camp this week, and Katie Kate can dance to keep your mind off of the test.”

“You can see Katie Kate?” exclaimed Claire.

“Sure,” said Andrew. “She’s a hero to all kids who have to be brave and take tests.”

“It’s true! I’m here to help!” said Katie Kate.

Andrew held Claire’s hand and they began to sing while Katie Kate hopped to the tune. Claire did a great job by holding very still.
“You’re all finished, Claire!” said Katie Kate as she pressed a big colorful sticker that said “I’M A TRIALNET HERO” on Claire’s shirt. “You were so brave and did such a great job. Thank you so much for helping today!”

“That was it?” said Claire. “That hardly hurt at all. It felt just like a tiny pinch.”

Claire left camp that day with a very special feeling inside. She had been worried about the blood test, but she thought about Andrew and all the other kids she had met who were living with diabetes. She made a big decision. She decided it was important to help find a way to keep other kids from getting diabetes. Claire really was a hero!
All kids like Claire, who have a brother or sister with diabetes, are special and can help scientists find a way to keep other kids from getting diabetes. Even if they do not want to have a blood test, they can be a hero by supporting their sister or brother with diabetes. And they can participate in diabetes organizations and community events to help people learn about diabetes and to tell others about the importance of research.

There will be times in the future when you will receive the call to be a hero. When that time comes, think about all the things Katie Kate said to make Claire feel brave and you will be ready to join the mission!
Type 1 diabetes is an autoimmune disease in which the immune system attacks and destroys the cells in the pancreas that produce insulin. Proteins called autoantibodies are markers for the destruction of these cells.

TrialNet is an international network of researchers who are exploring ways to prevent, delay, and provide early treatment for type 1 diabetes. TrialNet offers a screening test that can detect these autoantibodies in the blood up to ten years before someone is diagnosed with type 1 diabetes. A major goal of the TrialNet studies is to delay or prevent diabetes in people with these autoantibodies.

Only 4 to 5 percent of relatives tested will have autoantibodies. If positive, participants can be monitored in the Pathway to Prevention study and will be offered enrollment in a prevention study, if eligible. Benefits to monitoring include early detection of type 1 diabetes, which may help maintain insulin secretion and avoid dangerous complications.

You can find out whether you or your children are at risk for type 1 diabetes if:

- you or your children are one to forty-five years old and you have a parent, child, brother, or sister with type 1 diabetes, or
- you or your children are one to twenty years old and have a niece, nephew, aunt, uncle, grandparent, half sibling, or cousin with type 1 diabetes.

If either of these applies, you or your children can have a blood test as part of the Pathway to Prevention study. TrialNet has over two hundred study centers. Screenings are provided at no cost. To find the study center that is closest to you, visit www.diabetestrialnet.org or call 1-800-425-8361.

You can also provide your consent by going online at www.pathway2prevention.org.

At no cost, TrialNet will mail you a test kit that can be taken to a local lab to be administered by a healthcare professional. The sample will be mailed directly to TrialNet, and results will be reported within six weeks.
More About Summer Day Camp for Children with Diabetes

The screening test described in this story is performed with the consent of the child’s parent. The story takes place at a diabetes day camp, where children with diabetes and their sisters and brothers without diabetes can attend together. We recognize that not every diabetes camp offers this arrangement. To find out more about diabetes camps and specific programs offered in your area, contact the Diabetes Education & Camping Association (DECA) at www.diabetescamps.org.
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ABOUT THE AUTHOR

M. Maitland DeLand, M.D., is a radiation oncologist specializing in the treatment of women’s and children’s cancer. She is the founder and former owner of Oncologics, a group of cancer treatment centers in the southern United States. One of the leaders in her field, she is the chairman of the Health Education Authority of Louisiana Board that serves to promote medical education, research, and healthcare throughout the state. Dr. DeLand also serves as a member of the Breastcancer.org Professional Advisory Board. She has dedicated her career to helping her patients and their families lead balanced and rewarding lives.

ABOUT THE ILLUSTRATOR

Jennifer Zivoin is a children’s book illustrator living in Carmel, Indiana. Although she has been trained in media ranging from figure drawing to virtual reality, her passion is bringing stories to life through her watercolor paintings. Her most recent work has been creating illustrations for Brian James’s popular Pirate School series.