

All Heart

By Tammy Trout

They say snips and snails and puppy dog tails are what little boys are made of. Jonathan Mitchell has a few extra parts. He also has a pacemaker.

Most people get pacemakers when their hearts start to wear out. Jonathan got his first one when his heart had barely gotten started. He was only 2 years old. By age 8, he needed a more advanced pacemaker and had been through multiple heart surgeries. At 9 years old, Jonathan is doing his best to be like any other little boy. The thing is, Jonathan is different, because he is special.

Although it doesn't physically work just right, no one has a more giving heart than Jonathan. It powers an infectious smile, a curious mind and a video game obsession.

He plays with Philip and Eric and C.J. and the other boys in his neighborhood. He has to play two-hand touch football instead of tackle, but they ride bikes and shoot hoops and goof off just like other little boys. "I kind of get to do what I want," Jonathan says, "but I know I shouldn't get hit."

For Jonathan, that means playing at karate instead of actually kicking and punching, but it doesn't mean not playing at all.

Jonathan Mitchell, 9, has been living with a pacemaker since he was 2, but it hasn't slowed him down.

"Jonathan knows how to pace himself. He knows when to stop and rest, but that doesn't stop him from playing," says Katherine Strozier, Jonathan's legal guardian. She's been Jonathan's primary caregiver since he was 9 months old. His father, who was awarded custody of Jonathan, lived in her neighborhood, so she looked after the baby more and more. But she knew something wasn't right. He was too blue and puffy. He wasn't getting all the proper medication. "I wanted to keep him and make sure he was looked after," she says.

Though Jonathan still sees his dad occasionally that decision turned out to be best for everyone. He is all smiles when it comes to his "mom" Katherine, saying he knows he "got a really good

deal." He even got sisters – Katherine has a daughter who is 27 and twin girls who are 25 who also help out.

Katherine knows something about raising kids, but Jonathan has been a challenge. A delightful, precious challenge.

Jonathan was born with multiple heart defects, including an atrioventricular septal defect, which means his heart chambers and valves did not form correctly. He also had an obstruction

in the tube that allows blood to flow out of the heart to the body.

If all this sounds serious, it's because it is. "Jonathan has had a lot of reconstruction, which can lead to arrhythmia. He now has abnormal rhythms in both the upper and lower chambers that can result in decreased blood flow out of the heart," says Debbie Auld, one of the nurses on the team at Egleston Children's Hospital who has cared for Jonathan for most of his life. "One type is ventricular tachycardia, which is life-threatening among adults, and certainly for Jonathan."

"I've tried to be totally honest with Jonathan about his condition," Katherine says. "I want him to understand so he can be careful." They talk about everything. She doesn't gloss over



anything, so Jonathan is more savvy than people three times his age about his heart condition and his life. He takes a lot of medication, but he knows exactly what each pill is for and when he's supposed to take each one. Now he's taking five different medications. That's a lot for anyone to grasp.

He says he likes school "ok," but really enjoys science. That makes sense. Jonathan knows more about biology than many college students. He lives it every day.

When he went into arrhythmia at school, he understood what was happening and told his teacher. He also knew enough to stay calm until doctors could get his heart rhythm back to normal. Most adults wouldn't be able to do that. But Jonathan isn't like most other people. Despite his condition, he hardly ever looks sick. He's tall for his age, with the kind of eyelashes teenage girls dream about. The pacemaker? "I don't really worry about it," he says. "The old one is still in, but it's turned off. The newest one is by my shoulder, but you hardly know."

With Jonathan, you don't notice what's wrong. Instead, all the right things shine every time he smiles – which is most of the time.

Being in the hospital isn't pleasant for anyone, but when Jonathan is there, he makes the best of it, not just for himself, but for everyone on the floor.

"Sometimes I visit the other kids," he says. "Sometimes they are really sick and don't have much fun. I decide to help sometimes." Roger, and Jacob and Darius and many other patients and their parents are glad he cares. "Sometimes I hear someone

crying. I go in and talk and play so they won't be scared," Jonathan says. It also cuts down on hospital boredom.

And when you're as curious as Jonathan, sometimes it takes a lot to stay interested. "But I can always play with my video games," he says, like any other little boy.

Katherine says she hopes to involve Jonathan in the hospital's "Kids at Heart" program for children with similar conditions. "I think he would be so good," she says. "All he wants in return is a hug." Though they hate to see any child often, the hospital staff is totally taken with the mischievous Jonathan, even when he wants to toss a football down the halls. "Jonathan has a special place in my heart," Debbie says.

"Everyone here loves him. You just can't help it, but all the children make you realize how important it is to live each day without worrying about tomorrow.

"Jonathan has grown up so fast," she says. "He lost some innocence to gain some control of his life, but he's still such a joy. He makes us all smile every day we see him."

Kenneth Dooley, MD, one of Jonathan's doctors, agrees, "He's something else. Right now, the medications seem to be working. He seems to be responding well." And the Tootsie Rolls the good doctor slips into Jonathan's hands don't hurt either. (Being Jonathan, he offers to share, of course.)

After getting the new pacemaker when he was 8, Jonathan only went to the doctor for routine checkups for quite a while. "We've been blessed," Katherine says, even though he had a real scare recently with the arrhythmia episodes and sick sinus syndrome. Doctors also had to put a catheter into his heart not long ago to find an abnormality so they could correct it.

For Katherine, the joys far outweigh the distress. It isn't easy to balance working, paying bills – and there are a lot of bills – juggling insurance claims, and monitoring medication with the normal homework and headaches of a 9-year-old.

"I worry about him, but I believe in him. I want him to understand what's wrong so he can deal with it, but I don't want to keep him from being as normal as he can be. And he is normal most of the time now," Katherine says.

"It was really tough when he was little, but I had help. With my daughters, we made sure Jonathan was always cared for. And with everything, he was such a sweet baby."

Katherine even gave up her job for a while because Jonathan required so much care. Since he's been doing well and can even participate in an after-school program, she's been able to resume working. Medicaid pays for many of Jonathan's medical

expenses, but there is always something. Like when he started a new medication that wasn't yet covered. It was expensive, but Katherine found a way. She always finds a way. Anything to make his warm brown eyes twinkle.

At first glance, Jonathan might look like any other little boy. On the outside, he loves basketball, the "Magic School Bus," Nintendo and SEGA, snakes and hot wings. His eyes give away the differences he holds inside.

Part of the difference is a heart that doesn't always work right; but a bad heart is just part of what sets Jonathan apart. His heart condition forced Jonathan to mature mentally, far ahead of his body. In many ways, he has the heart and mind of a much older man.

Fortunately, Jonathan still has the spirit of a child.

