

Walking in HOPE

When their faith was shaken, a Covenant pastor and his family found that God had not abandoned them.

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AS A KINDERGARTNER growing up in Visalia, California, Andrew Boynton loved make-believe. Pretending he was Indiana Jones, Andrew, a little blond ball of energy, would belt out the *Raiders of the Lost Ark* theme song, jump onto playground equipment, and brandish an imaginary bullwhip.

So it was a surprise to Andrew's parents when his kindergarten teacher told them she thought there was something physically wrong with their son. "There were red flags to her," Tracey Boynton, Andrew's mother, recalls.

For example, Andrew had trouble getting up after sitting cross-legged. And he tended to stumble when he walked. Up until then, Andrew's parents had overlooked his occasional clumsiness, attributing it to Andrew's fondness for walking around with his nose buried in a book.

"We thought he was just not watching. All the things we could have

noticed as suspicious, we thought, "Those are just Andrew things," says Tracey, whose husband, Tim, is pastor of Kingsburg Evangelical Covenant Church in central California.

But Andrew's teacher was right to worry. Those quirks, first noticed in 1998, eventually led to a devastating diagnosis in January 2002—not just for Andrew but for his younger sister, Kennan, as well. It was the start of a journey of faith for the family of five, which also includes Luke, the middle child. Every doctor's visit and medical test that followed moved the Boyntons further along that path.

The diagnosis

The Boyntons followed the recommendation of Andrew's teacher in 1998 and took their son to see the doctor. When their pediatrician was stymied, they took Andrew to a specialist. Over the next four years, they would go from doctor to doctor, but none was able to figure out what was causing Andrew

to shake and stumble. Everything from muscular dystrophy to cerebral palsy to a harmless developmental glitch was suspected. As time went by, Andrew's health only seemed to worsen.

Finally a pediatric neurologist at Children's Hospital Central California in Madera sent Andrew to a genetic counselor. In January 2002, a brand-new blood test at last revealed his condition: Friedreich's ataxia, a debilitating neurological condition that causes the degeneration of the nervous system, resulting in the progressive loss of muscle control but not harming the ability to think. Affecting about one out of 50,000 Americans, the condition may also cause heart disease and a shorter life expectancy. There is no cure or effective treatment.

The news stunned Tracey. As a teacher, she was accustomed to solving problems by methodically gathering information and studying it. But no amount of data could help her undo this diagnosis. She remembers shop-



Church members Robin Peterson (right) and Brian Johnson (center) welcome Andrew when he returned to church following spinal-fusion surgery in September.

ping at Cost Plus World Market following the family's first appointment with the geneticist. Wandering among the boxes of exotic teas and tins of imported food in the back of the store, she suddenly found herself gasping for breath. She thought to herself, "I'm going to lose it here. I'm going to start crying. I can't do this in the middle of Cost Plus."

"That's when it really hit me," she says. "This is real. Everything is different now. The sadness of it hit me."

Though shaken, Tracey managed to regain her composure and the moment passed. But nothing would be the same again.

The diagnosis threw Tim into a tail-

spin as well. "I remember in general... being overwhelmed," he says. "All parents dream things are going to be great for their kids—and I just remember all that being dashed."

But God was present even in those initial dark days, the Boyntons say. A month after the diagnosis, Tim was in Chicago at the Covenant Midwinter Conference for ministers while Andrew was scheduled to undergo a series of heart tests back home. One dominant factor that determines lifespan for people with Friedreich's ataxia is whether the condition affects the heart.

"We asked the church to pray; God can do amazing things," Tim says, expecting a good test result. He was in

a workshop when Tracey called with the news: Andrew's heart was damaged. Tim returned to his hotel room devastated. He paced back and forth, crying and angry—really angry, he says—and thinking that God had let them down.

He prayed aloud: "We're your children. We love you. We know we're not perfect; we don't have perfect faith. What more do you need from us?"

At that moment, Tim says, it was as if God embraced him. "He wrapped arms around me," he says, thinking

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back on the moment. "He didn't give me any answer—just wrapped his arms around me."

It was then that Tim knew, despite the diagnosis, God had not abandoned them. "We do not walk through the valley of the shadow of death by ourselves," Tim says. "He's walking with us."

Tracey felt God speak to her, too, within weeks of Andrew's diagnosis. Sitting on her living-room couch on February 7, 2002, preparing for a Bible study, she read from Isaiah 40: "The LORD... gives strength to the weary and increases the power of the weak. Even youths grow tired and weary, and young men stumble and fall; but those who hope in the LORD will renew their strength. They will soar on wings like eagles; they will run and not grow weary, they will walk and not be faint" (vv. 29-31, TNIV).

"As it hit me, I just got goosebumps," Tracey says, zeroing in on the image of young men stumbling and then soaring on wings like eagles. "It just really felt... that was for Andrew," she says. "That was for him."

When she showed the passage to Tim, tears formed in his eyes. "It was

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like I read it for the first time,” Tim says. “It was a real promise.”

The following week, the Boyntons received a package from Andrew’s school. He had been named student of the month for January and his school had sent a framed keepsake. In the paper frame was a picture of Andrew with his entire class and principal under the school mural, which reads: “Our Children Will Soar on Wings Like Eagles.”

The photo, taken before Andrew’s diagnosis, and the Isaiah passage gave the family a much-needed ray of hope—and an encouragement to keep their eyes focused on God.

“We’re open to him doing something miraculous. We’re leaving it in his hands as to how that plays out,” Tim says.

The body of Christ

In 2003, the Boyntons learned that their daughter Kennan also has Friedreich’s ataxia.

“It’s not easier to hear it for the second time,” Tracey told the *Fresno Bee* in an interview last summer. “When Kennan was about four, I saw her running and, in my heart, I knew she had it.”

Kennan, a chatty ten year old with naturally curly hair and a love of making new friends, walks with the wobbly gait typical of so many with Friedreich’s. Due to the disease, her heart is working harder than it should, which is causing extra pressure on her mitral valve. She may need to start taking beta blockers, as Andrew currently is doing.

Andrew, now fifteen, had spinal-fusion surgery in September, in which a U-shaped rod was inserted to straighten his posture, which had been hunched over due to scoliosis. He had been using a wheelchair since last January and a walker since fifth grade.

Members of Kingsburg Covenant have been a real source of strength through their ordeal, the Boyntons say. They have brought hot meals during stressful times, and have always been ready to lend a listening ear. When doctors’ appointments haven’t gone well, and after Tim and Tracy have vented their frustrations and worries, church members have spent time praying with them.

“That’s the thing that’s been really neat—to see the body of Christ be what we think it should be,” Tim says.

Having two children afflicted with a

genetic illness has changed the way Tim understands ministry. When he first arrived in Kingsburg, he thought, “I’m going to go help this church.” Now, he thinks, “maybe God had us move here so the church could help us.”

A number of people from church have formed special connections with the Boyntons.

Bill Ostrom, a soft-spoken pharmacist and former short-term missionary to Congo, has been reaching out to Andrew for a few years.

Before Andrew’s recent surgery, Bill wanted to do something special for him. Based on Andrew’s passion for medieval history, Bill wrote him a four-page letter pointing to the passage in Revelation 19 about the last battle, where Christ is on the white horse leading the armies.

“My vision for Andrew was to be the banner carrier,” Bill says, referring to the person who holds the army’s standard aloft for all to see. Bill encouraged Andrew to be a banner carrier by pointing other people to Jesus by living out his faith. One way to do that was by learning people’s names—from Andrew’s classmates to the doctors and nurses who treat him—and to learn



Kennan greets parishioners after church last fall, displaying her infectious enthusiasm and love for people.

something about each person. That way Andrew would be able to encourage other people when he talked to them. "Names are important to God," Bill says. "God can use that in a very powerful way."

Bearing fruit for God's kingdom

The Boyntons realize God has already used them and their circumstances to bear witness to his glory in ways both big and small. Most recently, Andrew's speedy post-surgery recovery, which surprised the hospital staff, revealed God's goodness, the family says.

He stayed in the hospital just seven days, despite complications during the surgery, including a punctured lung and a nicked carotid artery. He had been expected to be hospitalized for ten days, Tim says. "We have a lot of people praying," he adds.

According to Tracey, the family's ordeal has enabled them to understand and speak with people who are going through difficulties. "We have a realness about us, because of what we've been through, that allows people to talk," she says.

In particular she has been able to witness through an email group for parents of kids with Friedrich's. She recalled one unchurched couple who had started buying their son anything he wanted, to help him cope with the disease. But Tracey advised them that the void their son felt would never be filled by material possessions, but only by God. She encouraged them to go to church. Recently, Tracey learned the woman, her husband, and their son had been baptized as a result.

Another woman, who already had one child with Friedrich's ataxia, became pregnant again and emailed the group desperate for advice. She was fearful that the baby she was carrying would have the condition. "Anyone out there have two? I just don't know if I can handle it," she wrote.

"She was really thinking of having

an abortion," Tracey said. "I said, 'I have two.'"

In fact, Tracey and Andrew had talked the day before about what Tracey would have done if she and Tim had known their kids might end up with Friedrich's. Maybe, she said, it would have been too much to bear and they would have decided not to have children.

Andrew spoke up. "I'm so glad you



The Boynton family: Tracey, Luke, and Tim, with Andrew and Kennan in front

didn't know," he told his parents. "I'm glad I had the chance to be born."

"That was real confirmation—right from the source," Tracey says. "Despite the difficulties and struggles, he was glad he was here."

She relayed Andrew's comments to the pregnant woman, who thanked her. "She had that child," Tracey says.

Dreaming big

Today, ten years after the first signs of the disease, the Boyntons are in many ways like any other family in Kingsburg. They have two dogs, Nutmeg and Poppy. The kids tease each other. They spend time with friends.

Andrew is a high-school freshman who recently became a published au-

thor. A story he wrote about Admiral Lord Nelson was accepted into a book of historical biographies. He hopes to attend Oxford University.

Luke, twelve, likes to skateboard. He's learning woodworking, both at school and after school at the home of a church member who is a skilled woodworker. He hasn't found his passion yet, Tracey says, "but when he finds the right thing, he'll be 'all in' because that is his personality."

Kennan is a fourth-grader who loves school and animals. She hopes to become a veterinarian or work for the ASPCA so she can help save and rescue animals. In the meantime, she has fun feeding Nutmeg and Poppy under the dining-room table.

When Tracey contemplates her kids' futures, she said she hopes they can do whatever they want as best they can. The couple encourages their children to make big plans, even as Andrew and Kennan are losing some of their ability to function.

"Dream big, and we'll see what happens. Why not?" Tracey says.

Being published was one of Andrew's goals, and Tracey feels it was important to help him accomplish it. "I don't know how many opportunities he'll have for that dream," she says. "He may

live a very long life and have a lot of opportunities—and he may not."

For Tim, his central hope for his children is spiritual.

"I would love for them to have that personal relationship with God," he says, smiling, as he often does. If God was to heal them, he says, he hopes they would spend the rest of their lives telling others about the miracle.

Tim admits that even now he and Tracey still struggle as the disease marches on in their children. "Sometimes we feel really confident; other times we feel beat up," he says.

But overall, he's in a better place than he was a decade ago. "I feel a lot more hopeful now—a lot more confident in the Lord." □