

# BLESSING AKEWAK



## The World Made Small: One Boy's Journey from Ethiopia to Denver

By Nancy Sharp

Photographs By Tracy Pliskin

*A cow gave birth to a fire: She wanted to lick it, but it burned; she wanted to leave it, but she could not because it was her own child.*

Proverbs such as this one, which speaks of parental love and commitment, are how the people of Ethiopia, where illiteracy is rampant, express their inner feelings and teach their children. In the United States, we have a broader saying for such responsibility:

*It takes a village to raise a child.*

A doctor from New York and a family in Denver, defining their village as the world, shouldered that responsibility for one child of Ethiopia and, in the case of the doctor, hundreds more. Akewak Behailu Wondimu, who has loving parents in Africa, was fortunate that he came to the attention of Dr. Rick Hodes and his host family, Kim Schneider and Charles Malek. Akewak's American village is working hard to ensure that he isn't the last.

Hodes has been answering the call of the proverb and the saying for more than 20 years. Born in Long Island, Hodes is medical director of Ethiopia for the American Jewish Joint Distribution Committee and senior physician at Mother Theresa's Mission. He has dedicated his life to helping the most vulnerable of Ethiopia's children, those with cancer and severe physical deformities, some of whom are orphans and others whose families cannot afford to care for them. Spend a few minutes with him and he'll tell you why he

chooses this life: "He who saves one, saves an entire world," he often says. This philosophy is derived from the Talmud, a collection of sacred Jewish writings. For his patients, Hodes provides medical treatment, oversees their education and, when necessary, opens his modest home to house them. He has adopted five Ethiopian children, the maximum number allowed. Earlier this year, an HBO documentary, *Making the Crooked Straight*, and a book, *This Is the Soul*, were released about his extraordinary humanitarianism.

Without knowing it, Denver's Kim Schneider also responded to the Ethiopian proverb's subliminal message of every child being her child. Schneider and her husband, Charles Malek, have three small children. Schneider traveled to Ethiopia in February as part of a mission coordinated by the Jewish Federation of North America to escort 126 Ethiopians of Jewish ancestry to Israel. Along the way she spent much time with Hodes, never expecting that through him, she would meet a boy needing a heart surgery and a host family.

Akewak was 13 and weighed a scant 58 pounds when Schneider first met him in February, sitting on the stoop of Mother Theresa's clinic in Addis Ababa with his mother. He wore a black sweat jacket and a scared face. "In spite of his fear," said Schneider, "he smiled at me with warm brown eyes, and his whole face lit up. In my heart, I knew that I would do anything to help him."

Akewak was born with VACTERL syndrome, a congenital condition associated with heart, limb and spine anomalies.



He had a large hump in his back and was born without a right thumb.

Akewak had come to Hodes' attention just a few weeks before Schneider's trip to Ethiopia. He and his parents went to see Hodes at his clinic. They were concerned about Akewak's back. "Right away I could see that the huge bulge in his lower back was stunting his growth," said Hodes, who also noted the scar on the boy's chest from heart surgery six years earlier.

"He came to me about the problem with his spine, but it was his heart that alarmed me. When I listened closely with my stethoscope, I heard a loud-machinery type of murmur."

Such a distinguishable murmur usually signifies an open blood vessel from the aorta to the pulmonary artery. That can lead to pulmonary hypertension, which is fatal.

Hodes remembers shaking his head in disbelief; this problem supposedly was taken care of during Akewak's initial surgery. In fact, it was why he had the surgery. Hodes quickly ordered an echocardiogram, which showed not only that the blood vessel was still open, but also that the doctors had tied the wrong pulmonary artery and failed to detect their mistake. Akewak's father, a policeman, was rightfully angry, telling Hodes, "My son went to the doctor so many times and they said he's fine. Now, he comes to you for a bad back and you're saying that his heart will kill him?"

It wasn't until April that Schneider and her husband learned that Akewak was confirmed to arrive in Denver the following month. Hodes had reached out to pediatrician Dr. Steve Berman at The Children's Hospital, whom he had met when his film was screened at the 2010 Denver Jewish Family Festival.





flushed and a hot shower to use anytime he wanted. Back in his hometown of Burayu, he lives in a two-bedroom house with his parents and shares a room with his three siblings. Akewak and his older brother, Abraham, sleep in one single twin bed, while his sisters sleep in the other. The family uses an underground toilet and a bucket to wash themselves.

"Everything was new for Akewak," says Schneider. "He had never flushed a toilet before, never used a knife to cut food with, and never seen dessert."

"It took some time to get used to my host family and the way they do things," said Akewak, who admittedly missed his family back home even as he was drawn to the luxuries of American

"With all the expertise that The Children's Hospital has, I thought it would be very special to be able to do something to help him," said Berman, who immediately enlisted the support of Dr. Mike Schaffer, a pediatric cardiologist. The process took about a month, but together, Berman and Schaffer rallied a heart surgeon, Dr. Dave Campbell, and an orthopedic surgeon, Dr. Mark Erickson. Both agreed to donate their services. Berman then advocated Akewak's case to a special team within hospital administration, which decided that Children's would care for the boy pro bono. The ready cooperation of all parties explains why Akewak's procedures and convalescence were planned for Denver.

So on May 23, Hodes escorted Akewak on his long trip. He had never been on an airplane and came with only a black carry-on suitcase that had two pairs each of underwear, socks, pants, shirts and embroidered royal blue and black pajamas that his mother had bought for him to wear with pride as a reminder of his culture. "I learned how to be brave and scared at the same time," he said.

"We were very happy to welcome Akewak into our home," says Malek. Right away the couple's three children were captivated by this new person coming to stay with their family. Five-year-old Molly was instantly protective, says Schneider. "She really didn't want to share him." Yet twin 3-year-olds Henry and Jacob fawned over their new playmate. The age differences between the siblings and Akewak soon collapsed over games of hide and seek. "Chase me, chase me," the children sang to him. In a matter of days, Akewak had become a surrogate brother and son.

Still, it was hard to ignore that Akewak's life in Ethiopia was a world apart from his new surroundings. Here in Denver, he had his own room, his own bed, a toilet that

culture. "Just seeing all the toys the kids had made me sad, because I never had any of that."

Schneider and Malek have large families and a wide network of friends (including this author), all of whom wanted to lend support and make Akewak's experience in Denver as meaningful as possible. Family and friends rallied around Akewak for his heart surgery on June 1, when Campbell and his team rebuilt the pulmonary artery that had been tied off. And they were there for Akewak's spinal fusion on Aug. 25, which prevented the curve in his back from worsening and crushing his chest.



Akewak was in a lot of pain when he left the hospital following this second procedure, so Schneider organized a volunteer brigade to help him recover. People visited daily, sat beside him, played games and, when he was well enough, helped him walk about. Cousins did informal home schooling with him, working on language, reading and math from curriculums that Schneider had purchased.

Between doctors' appointments and his two surgeries, Akewak's extended Denver family took him to museums, the Denver Zoo, the movies, Water World, sleepovers and bike excursions in Washington Park. He taught himself to play Nintendo, surf the Internet and ride a bike. So many firsts - including the chance to go to an American school for three weeks. In September, after he had recovered from his spinal fusion, Akewak joined the sixth grade class at the Jewish Day School, studying poetry, algebra and geometry while giving his peers a lesson in courage.

Throughout his five-month stay, many lessons were learned, by Akewak and his host family. "We take for granted that our lifestyles are full of easy access," says Schneider. She remembers that Akewak was so curious at first, touching everything, downloading computer games and ordering \$44.99 worth of wrestling programming on television without realizing the cost. "He had no idea this was not allowed, because everything in his experience said, if it's accessible, it's yours." But he learned quickly.

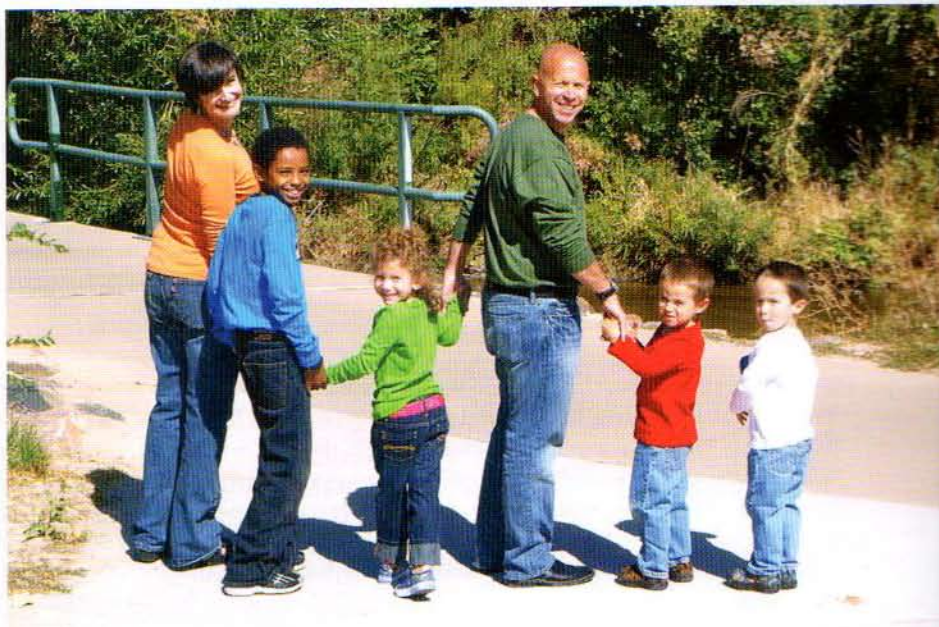
"It's always big to take someone into your home," says Malek. "But you do what's needed at the moment, and what you would want done for you."

For Schneider, the experience has been life-changing, bringing her family closer across the generations, from her 3-year-old twins to her 77-year-old father, who served as a surrogate grandpa. "We've all grown from coming together in this way to celebrate the life and spirit of Akewak."

With his surgeries and medical ailments behind him, Akewak can now live as he wishes, maybe someday fulfilling his dream of becoming a doctor in Ethiopia, working alongside Hodes, his hero. "So much goodness has been shown to me," said Akewak. "I hope that someday I can give back, helping other children like me."

Days before heading back to Ethiopia in October, only one thing remained that he wanted to do: indoor skydiving. With all that he had endured, Akewak wanted to fly now in a different way, to prove that he was brave enough, healthy enough, vital enough to soar. "He was just beaming," said Schneider. "Over and over that last week he sang the verse, 'I believe I can fly, I believe I can touch the sky.'"

The boy with the smile as bright as the Colorado sky weighed more and stood taller and straighter when he left - in pounds, inches and courageous spirit. He's home in



Ethiopia now, a year older and with many books, puzzles, Legos, gently used clothing for his family and a flip camera given to him as a way to journal his American experiences. He is healed in the deepest possible sense. For Kim Schneider and her family and the Denver village that came to know and love him, it will take some time to imagine their lives without Akewak Behailu Wondimu. Yet, in truth, he is only a proverb away. ☺

#### Letter from Home

Akewak's mother sends a message of love

Dear Kim !

How are you and your family? we met akewak last sunday, he become tall and fat it seems like every thing was very comfortable for him. I don't really know how to thank you, just no word to explain my feeling for you.

Firstly I would like to thank our respected brother Dr. Rick, who helped us to get a lovely sister like you. Generally I would like to thank those who were striving to cure him so quickly and gave him hope to survive,

- Dr. Richard Hods

- You and your entire family

- All akewak's Doctors

- for those who visited him and tried to fulfill all his needs and who were always by his side. Specially my lovely Kim. We like to explain our love and respect for all of you. We wish peace, love happiness and success in your life. GOD BLESS YOU.

Tsedale