



Father: A long, lonely journey to find care for a young son

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oped a constellation of four separate defects known as tetralogy of Fallot, or ToF, that gets its strange name from the French physician who first described the condition. It's not rare; each year about 3,000 babies in the United States are born with ToF. With surgery, the cure rate is near 100 percent. Without surgery, the heart becomes increasingly dysfunctional and the organs, without enough oxygen, fail. Eventually the heart gives out, too.

Ali has many of the classic symptoms of ToF. Too little oxygen in his body gives his skin a bluish tint, particularly visible on his nail beds, his lips and in the thin skin around his large brown eyes. Instead of standing straight, he often squats down to the floor, instinctively pushing oxygen into his brain. When it's hot out, or if he gets upset or dehydrated, he sometimes faints.

Unable to bear the loss of another son, the family sought help from a humanitarian organization in Iraq. They had little money. Kareem was a plumber then, though he has now been out of work for a couple of years. The Iraqi organization referred them to the National Iraqi Assistance Center, a multi-national program started and managed by the U.S. military. Ali was two months old.

After some dead ends, the National Iraqi Assistance Center gave Ali's medical records to Our Children International. Founded in 2005 by Upper Saddle River resident Sue Vallese, this organization brings disadvantaged children to this country for medical treatment. Through Our Children International and the Gift of Life, a rotary program, Ali's medical records found their way into the hands of cardiologists at St. Joseph's. They decided last spring to take on the case.

The two groups paid for the expenses of getting to the United States. They arranged for Kareem and Ali's stay and paid the medical bills. The doctors waived most of their fees. The hospital donated all costs but the disposable items used for the surgery — about \$6,000 compared to upwards of \$100,000 that it usually would cost for such a complicated procedure. Still, to cover his expenses, including bus tickets to the airport in Kuwait, Kareem sold most of the family's possessions, including their television, oven and refrigerator. He sold their 1991 Opel that he had been using as a taxi to earn money. He sold their beds and moved the family in with his parents.

In the most personal sense, Kareem has benefited from the American-led invasion of Iraq. Not only did he receive help from a U.S. military organization, but Ali's treatment also has been paid for in U.S. dollars. Yet, he does not see himself being helped by America. *I am accepting charity from good people who happen to live in America*, he says through a translator. *It is not the same America that invaded Iraq.*

You have to fix them

Two days before Ali is scheduled for surgery, he squats on the floor while eating a blueberry muffin at Vallese's house. He has been playing with Vallese's two daughters, who taught the boy to say "OK" and "Bye," and he repeats his newly learned English often. Suddenly, his breath becomes rapid and shallow. He starts whimpering slowly and reaching for his father. As Kareem picks him up, his eyes glaze over and he goes limp, a rag doll in his father's arms. Kareem pulls Ali's thighs to his chest to help him breathe. His lips and nose take on a deeper bluish hue as he falls unconscious.

After a few minutes, he begins to recover. The boy's breathing slows to a more normal rhythm, but he is exhausted. He barely responds when his mother calls from Baghdad, though he's been crying for her since he arrived.

When you have a child who faints on you, Kareem says, they are almost dead and then they come back to life. You know you have to fix them.

Ali does not recover well from that spell. He is admitted to the hospital early so that they can keep fluids in him and watch him before his surgery. Ali, normally a happy and popular boy, his father says, is not happy in the hospital. In the hospital, he is scared.

Ali tries to pull out the lines and tubes that keep him hydrated and give him oxygen. He rolls over in his bed when the nurses aren't looking. Because of this, they sedate the little boy. When the nurses wheel him to the operating room in the early morning, Ali is calm.

He turns his head toward his fa-

ther when Kareem leans in to kiss his son's face and stroke his shiny black hair. He doesn't cry when Kareem pulls a copy of the Koran from his breast pocket and touches it to his own forehead, and then turns and walks away. Ali is quiet when the nurses wheel him toward the operating room for surgery.

By 1 o'clock, Ali is finished with surgery. It is successful and, thankfully, uneventful, says Stephen Walker, an advanced practice nurse at St. Joseph's who participated in the operation. Ali lies in an adult-sized bed in the pediatric intensive care unit. He's already small for his age and the bed makes him look like a baby. He's still sedated and cries when he begins to awaken. But his skin is no longer blue. His lips look especially brilliant, a plump, healthy pink. His heart is now able to pump enough oxygen through his body to keep his organs saturated. He will no longer squat to get oxygen to his brain or faint when he gets upset.

Kareem sits by his bed, often watching the monitors or shifting the blankets and pillows to make Ali more comfortable or just gazing at and caressing his son. Kareem says he's tired, both physically and psychologically. Complications, if there are any, will likely show up during this time — and up to 48 hours after surgery — and Kareem is still scared.

Though Kareem does not know it right now, during the surgery the doctors found a dimple in Ali's back that could be the sign of a potentially debilitating neurological condition. They will give him an MRI scan and, if it confirms their suspicions, Ali and Kareem might need to come back to the United States in a few months for another surgery. By not telling Kareem,



AMY NEWMAN/Herald News

Kareem Abdullah Mahdi of Baghdad watches his 2-and-a-half-year-old son, Ali, rest after having heart surgery at St. Joseph's Regional Medical Center in Paterson.

the hospital is taking care of him, too, treating him carefully, as if he is as fragile as a patient.

During the long hours Kareem spends next to Ali's bedside, with only the company of machines that beep and whir for reasons he does not know, he worries about going back to Iraq. The war has

made the situation scary, he says, and he fears bringing his son back to that environment. Though he brags about how the healthcare system used to be, he says now it has been decimated. He worries his son will not be able to receive the follow-up care he needs.

Ali begins drinking juice and

eating a few potato chips a couple of days after surgery. Though he hasn't gotten out of bed yet, it's likely that he'll be up and running around soon. When that day comes, Kareem says, smiling, he'll sit back and watch him go.

Today, though, Ali is still tired. He wants his mom. He looks up at

his dad crying, *I'm scared. Don't leave me.* Kareem walks over and sits next to his bed. He strokes Ali's hair. He takes out a book of prayers and lays it above his son's head. Ali falls asleep.

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