



Fahad's journey



by *Sylvia D. Campbell, MD, FACS*

I found the following message one early morning when I opened my e-mail:

Am a Ugandan mother of three boys, my last born son who is only seven months old was two weeks ago diagnosed with a heart complication. The doctors at Mulago Heart Institute say he has a hole between the two wall chambers of the heart and on top of that one of the pulmonary arteries is so narrow that the amount of blood pumped to the lungs is minimal thereby affecting his breathing. It's so unfortunate that the condition cannot be rectified here in Uganda. I thought of contacting you in case you can be of help to me so my request to you is to kindly assist me where possible to save the life of my sweet baby. Any kind of assistance is highly appreciated.

And so began Fahad's journey

Fahad Bukenya had Tetralogy of Fallot. At five months of age, he began to weaken and become less active. He contracted malaria at six months of age and was seen in his local hospital, where his murmur was heard. He was then referred to Kampala, the capital city of Uganda, where at the Mulago Heart Institute the diagnosis was made with an echocardiogram. His aortic override was 40 percent, his parachlorophenylalanine was 9 mm with confluent branch pulmonary arteries. No atrial septic defect, patent ductus arteriosus, or coarctation of the aorta was seen, and there was no VOT obstruction.

I have had the privilege of working with Heidi Hess in Tampa, FL, who coordinates the Gift of Life program here run by Rotary International. It is a program to help children who are unable to have cardiac surgery in their own countries and has served so many with such great need. I knew that this baby must be helped, and I contacted Ms. Hess about him.

It was believed that Fahad would be an excellent candidate for repair, but that it should be done quickly. St. Joseph's Hospital in Tampa and Paul Chai, MD, an extremely talented cardiac

surgeon, reviewed the information and agreed to take his case.

Jeanne Hardin-Gres—a nurse anesthetist and my good friend and mentor—and I were leaving for Uganda in just three weeks to review and discuss the development of a medical complex that was being planned for the village of Papoli. Ideally, Fahad and his mother, Anne, would travel back with us, if details could be worked out.

I contacted a travel agent who, amazingly, was able to get seats for Fahad and his mother on the same airline flight. My friend and minister, Rev. John DeBevoise, at Palma Ceia Presbyterian Church, was able to raise the funds for the tickets for Fahad and Anne. A letter was then sent to Anne from the Gift of Life program to help with obtaining passports and visas for her and her son.

Fahad could barely eat, he could not sit up, and he did not smile, but he looked at people with enormous eyes that had great pain. Each breath was an effort. His nail beds and lips were blue, and he already had clubbing of his fingers. The first time I saw him, on a dark street in Kampala, my heart broke and was rebuilt...and I knew we must make this journey.

Anne was told by the U.S. Embassy that the staff would need to talk to me before visas could be granted. So after a week in the bush, we traveled on Friday morning to the capital to meet with representatives at the Embassy.

I was told at the front gate again and again that visas were not issued on Friday. I then met with a representative at the Embassy, and I was told there would be no problem obtaining the visas the next week. I told him, "You don't understand—we are leaving tonight. If this baby does not come with us, he will die. If he comes with us, he will have his only chance for life. You must do something." Four hours later, we walked out of the Embassy with passports and visas. I do not know his name, but this man was truly an angel.

The trip to Tampa

We left Kampala at midnight to begin the 24-hour trip back to Tampa. We stressed to Anne how important it was that Fahad not cry, as we were concerned about a tet spell, and we sedated him with Benadryl as needed. He was so weak

Opposite: left, top to bottom: Ms. Hardin-Gres, Dr. Campbell, Anne, and Fahad in Uganda checking in at the airport; Anne and Fahad on the morning of surgery; Fahad on the night of surgery; postoperative day one, recovering; Anne and Fahad in Dr. Campbell's garden. Opposite, right: Fahad on the night of surgery.



Dr. Campbell and Fahad.

I do not know why Fahad was put in front of me.
I do not know what the future will hold for him, nor for his family.
I do not know what God's greater plan may be.
But I do know that in a small village in Africa, a little boy laughs, and sings, and a family has been restored, thanks to the kindness of those in a country far away.
There is much in the world that is wrong.
But there is also much which is right.
And by reaching out to a child in need, a miracle has been shared both by those who have given it, and those who have received it.
And none of us are the same.

—*Sylvia D. Campbell, MD, FACS*

that he did not have the energy to cry, and the trip was amazingly uneventful.

However, on his preoperative appointment at the hospital, he was noted to have a significant thrombocytopenia, with his platelet count falling to 35,000. He also was noted to desaturate to an oxygen saturation of 19 percent when he cried. These laboratory values necessitated a week in the cardiac intensive care unit to determine that he had idiopathic thrombocytopenic purpura, thought to be secondary to a viral infection he had caught before leaving Uganda. All of his other workup, including a bone marrow analysis, was negative.

Even with the low platelets, it was believed that his surgery was critical, as he continued to desaturate and weaken.

The operation and recovery

Fahad was taken to the operating room on March 18, 2008. There, Dr. Chai was able to do an amazing job repairing his heart. His defect was closed and his stenosis resected. The technical skill of Dr. Chai and his team were evident as the surgery progressed. Fahad's stenosis was just under the valve, and extreme care had to be taken not to cause injury to the valve. His post-repair intraoperative echocardiogram showed excellent normal flow, and his tiny chest was closed. His heart, once purple, was now pink.

Fahad had an unremarkable recovery and

was discharged to my home on Good Friday. His platelets remained low but slowly responded to steroids. With the help of my dear friend Iris Alexander, the manager of the cardiac cath laboratory, an outpouring of community support was organized for Fahad and his mother.

He found his appetite and began to eat everything he could, especially mashed potatoes. He and his mother became part of my own family, as well as the extended family of our community where my husband, my children, and all who met him fell in love with his smile. He began to sing and laugh all the time, and when he returned to his home, six weeks later, he was able to stand. He grabbed everything, and was curious about all those who gave their support and who came to visit.

Fahad and Anne have returned to Uganda, where he should have a normal life, a life full of all the wonder and energy of any little boy, for his broken heart is now fixed. Ω

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