It takes a Village

Conjoined twins from Africa are separated by a talented team of health professionals.

Dr. Cindy Howard with twins Loice and Christine Onziga
The MIRACLE of Modern Medicine

BY BRUCE GOLDFARB

THE EXTRAORDINARY JOURNEY OF CHRISTINE AND LOICE ONZIGA, CONJOINED TWINS SEPARATED AT THE UNIVERSITY OF MARYLAND MEDICAL CENTER IN APRIL 2002, BEGAN ON THE OTHER SIDE OF THE WORLD, MORE THAN 7,000 MILES AWAY IN THE REMOTE VILLAGE OF LESIO IN THE KOBOKO AREA OF WESTERN UGANDA.

It is one of the most impoverished regions on earth, still recovering from strife and guerilla warfare that wracked the country during the 1970s and 1980s. “The area that the twins are from is the poorest and most unstable area in Uganda” says Sherri Shubin, M.D., who was the girls’ pediatrician in the United States. “There’s no running water, no electricity, and no paved roads.”

As a senior resident in the University of Maryland Medical Center, Shubin participated in an exchange program with the Makerere Medical School in Uganda’s capital, Kampala. The medical school’s 1,500-bed Mulago Hospital, the only teaching hospital in the country, serves a region plagued with a high infant mortality rate, malaria, measles, and diseases that thrive in crowded, unsanitary conditions.

“The high incidence of acute and serious illness among children is beyond anything we see in this country” says Cindy Howard, M.D., clinical professor of pediatrics in the School of Medicine, who has supervised groups of medical students and residents since 1997.

“Practicing medicine in Uganda is a great opportunity to learn how to work with limited resources. It reminds us all why we went into medicine in the first place” says Howard.

Senior residents in the exchange program spend two months at Mulago Hospital working with Makerere Medical School faculty and conducting research. They are not usually involved directly in patient care. “Our primary responsibility is to help teach the residents there” says Howard.

Mulago Hospital has a great reputation, but they are completely overwhelmed by the demand for care.”

THE EXPECTANT FAMILY

Loice and Christine’s parents, Gordon and Margret Onziga, live on a farm with their four-year-old daughter, Noelle, Gordon’s parents, and his five younger siblings. The family earns about a dollar a day raising sweet potatoes, corn, and the starchy cassava root.

In October, Margret was pregnant with what the couple thought would be their second child—and planned to deliver at home. But after nearly two days of labor, exhausted and slipping into delirium, Margret was carried nearly a mile on her father’s back to the nearest taxi stand. From there, she traveled 18 miles to a hospital across the Complete border in Aru. The hospital was unable to handle her delivery and put Margret on a bus to a hospital across the border in a town 15 miles away.

Christine and Loice were delivered Oct. 28, 2001, by cesarean section, to the amazement of everybody involved—particularly their parents, who were not expecting twins, much less conjoined twins.

Conjoined twins are extremely rare, occurring in about one of every 200,000 live births in the United States. About 200 pairs of conjoined twins are born annually around the world. For reasons that aren’t entirely clear, they are more common in Africa and India. The condition results when a single fertilized egg fails to separate into identical twins. Like identical twins, conjoined twins are always the same gender. About 70 percent are female.

Loice and Christine were connected by tissue running from their breastbone to their navel. This condition, known as thoracopagus, is the most common form of conjoined twins. It occurs in about 35 percent of cases and almost always affects the heart.

“When I first saw that they were connected, I was surprised,” Gordon says. “It was the first time for me to look at such babies. I had no idea they could be separated.”

The Onzigas intended to return home and let the babies live out their natural lives. Without surgery, about 50 percent of conjoined twins die before their first birthday. Because life expectancy is shorter in developing nations, Loice and Christine’s chances for survival were even lower.

Margret’s father said he had heard that surgery can be done to separate twins like Christine and Loice and persuaded Gordon and Margret to take the babies to Mulago Hospital, about 310 miles southeast in Kampala. Traveling to Kampala and staying in the city would be expensive. To finance their trip, the Onzigas sold nearly everything from their house and board a bus for the dusty, 10-hour ride to Kampala.

Before the separation, Christine and Loise were connected from the breastbone to the navel.

The Onzigas expected surgery to be a research project to study neonatal morbidity and mortality in the neonatal intensive care unit at Mulago Hospital. Working with Shubin and Howard was Sue Rhee, M.D., then a pediatric resident. The nursery was abuzz with talk of the “special” babies who had come from so far away. “We went to see them because conjoined twins are so rare and interesting,” she says.

During their first weeks, the babies showed signs of healthy growth, but not at an equal rate. Loice, the smaller infant, was not gaining weight as rapidly as Christine and the discrepancy in their size and weight would increase until their small bodies could no longer tolerate the stress.

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Fateful Encounters

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Gordon and Margret Onziga were devastated to learn that an
Loice and Christine returned home to Uganda in the role played by a medical team that included medical students, residents, pediatricians, nurses, therapists, and nutritionists who have cared for the girls from start to finish.”

Howard attributes that positive prognosis to “the huge investment of time, money, and energy.”

According to their doctors, they have recovered well since the surgery and have an excellent prognosis. “We were able to use all the equipment and personnel that we needed,” says Strauch.

The Onziga family (front right) with some members of the division of pediatric surgery, was not directly involved in the Onziga surgery, but provided advice to the team.

Howard and Strauch had met and talked to the Onzigas, and knew their options were running out. Once the doctors at Mulago asked Howard if she would take Christine and Loice to the University of Maryland Medical Center. It was their only hope.

“Margret says. “If we didn’t take them, they would die.”

Howard called Jay A. Perman, MD, chair of the Department of Pediatrics in the School of Medicine, and presented the case for the babies. “There weren’t in Africa to do the operation,” says Perman. “There weren’t in resources in Kampala to determine whether surgery was feasible.”

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“Margret recalls the first time she saw her babies after the surgery. "Two beautiful—and separate—baby girls. "I wanted to cry," she says."

After a brief stay in the medical center’s six-bed transitional unit, Loice and Christine were cared for in the Pediatric Intensive Care Unit at the University of Maryland Hospital for Children. Once the twins were discharged from the hospital, Margret and Gordon stayed at the nearby Ronald McDonald House while the babies received physical therapy and additional medical treatment.

The girls underwent physical therapy to strengthen muscles and learn to sit and stand. They were able to use a feeding tube while conjoined, and have since reached normal developmental milestones. Loice had a small hole in her heart that was repaired by a pediatric surgeon. The girls also had exactly the same heart rate. We thought there may be some of the conduction system of the heart going through the connection.”

With pacemakers standing by in case either girl developed an irregular cardiac rhythm, the surgeons clamped and then carefully severed the vessel connecting Loice and Christine’s hearts. Fortunately, their heart rate and blood pressure remained unchanged. By the fourth hour of surgery, the babies were completely separated. The remainder of the surgery consisted of closing the chest and abdominal wall with synthetic grafting material placed by plastic surgeons.

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