‘Your Baby Was Born Like This Because You Are Cursed’

“Your baby was born like this because you are cursed.”

In Kenya and other sub-Saharan countries, this is often pronounced to the mother of a baby born with spina bifida. Spina bifida (SB) is a crippling birth defect that leaves a portion of the spinal cord exposed on the back, preventing the function of nerves below the exposed area. Tragically, babies with SB are often considered to be of no value in sub-Saharan cultures.

In fact, Fransisca, a BethanyKids staff member who was born with spina bifida, was almost poisoned for her condition. Despite fear and uncertainty, Fransisca’s mother ran away to protect her newborn daughter.

Fransisca’s mother eventually returned to her community, but Fransisca was never accepted. Her own father called her a “useless child.” Because of their inferior social status, SB babies often go without any care. Or, they might be taken to a local practitioner of traditional medicine or a local government hospital. Since neither have knowledge in current SB treatments, or a neurosurgeon on staff, the babies are often sent home to die.

SB has a high rate of incidence in sub-Saharan Africa for two primary reasons: The maize that is a staple in their diet has been contaminated with mold that inhibits spinal cord formation, and women have not been educated about taking taking folic acid before conceiving. Folic acid supplements cost less than 50 cents per year. Maize, stored properly and fortified with folic acid, could significantly decrease the risk of SB. Unfortunately few families can afford it.

Spina Bifida Treatment as Ministry in Sub-Saharan Africa

After living her life as an outcast and even attempting to take her own life, Fransisca found hope as a young teen when she found herself near Kijabe, Kenya. She met Dr. Dick Bransford, a career missionary surgeon and pioneer in the surgical treatment of spina bifida in Kenya.

“When I came to Kijabe,” Fransisca explains, “people just gave me love and showed me that I’m a person loved by God; and I came to know what SB is.”

Dr. Bransford’s surgical procedure physically transformed Fransisca’s life in ways she had never dreamed and she felt valued for the first time in her life. She also found a new life in Christ and today, she is a BethanyKids spiritual counselor and teaches hygiene to children with disabilities.

Dr. Bransford began treating babies with SB in Kijabe in the late 1990s. A decade later, he was treating more than 250 babies each year. Considering the average children’s hospital in the U.S. with two to three pediatric surgeons treats 15-20 children per year, this number was extraordinary.

After Dr. Bransford retired, Dr. Albright, a pediatric neurosurgeon, and his wife, Susan Ferson, a pediatric nurse practitioner, moved to Kijabe to continue caring for children with SB. They also aspired to teach neurosurgeons and neurosurgery residents how to treat these children, and to do research to improve care.

“I worked alongside the nurses and chaplains to minister to the mothers and babies every day,” says Susan Ferson. “I saw the difference we made in these families’ lives—they arrived with children that no one wanted, that were thought to be cursed, and through their stay at BethanyKids, came to know that these children are cherished by God.”

Four years and 5,000 children later, Leland and Susan passed the torch to Dr. Humphrey Okechi, who was trained in pediatric neurosurgery by Dr. Albright. Under Dr. Okechi’s skilled

guidance, children like Fransisca continue to receive the care they need, and parents see that their children have value.

Hope and Healing Through BethanyKids

Every child with spina bifida who comes to BethanyKids is evaluated and tested for spine problems, hydrocephalus and infection in the spinal fluid or any foot deformity. Treatment generally consists of surgically closing the open spinal cord. This is done through a new technique developed by Dr. Albright and Dr. Okechi, which reduces the risk of post-operative wound complications as well as a common condition called “tethered spinal cord.”

Many babies with SB also have hydrocephalus, the abnormal accumulation of spinal fluid in the brain. For this condition, they may be given a traditional “shunt” that drains spinal fluid through a small tube from the head into the abdomen, or are given a new procedure called endoscopic third ventriculostomy. This method creates an opening so fluid blocked within the brain can exit into normal pathways.

After surgery, parents are taught how to care for their children—their neurosurgical needs their urological needs and their orthopedic needs. Follow-up appointments are made with BethanyKids nurses in 17 mobile clinics across Kenya. Each mother also receives a year’s supply of folic acid.

BethanyKids at Kijabe is the only place in Kenya that gives comprehensive care for medical needs from infancy throughout childhood and into adulthood, so children with SB continue to come in increasing numbers. The organization subsidizes the care for 85 percent of the children. For those living in poverty, BethanyKids may be their only hope.

“We offer not just the physical healing,” says Dr. Humphrey Okechi, BethanyKids’ current pediatric neurosurgeon, “but the emotional and spiritual context of their lives. It’s really a blessing to know that the kids didn’t just survive what could

have been a death sentence, but that they are actually thriving.”

The word has spread that BethanyKids welcomes children and provides effective treatment. Now, children with SB come from every region of Kenya and neighboring countries, sometimes traveling more than 24 hours to receive life-saving treatment. This tiny ministry, serving some of the most needy and underprivileged children of the region, surgically treats nearly 3,000 children each year. As a result of their unique and vital work, BethanyKids has garnered support from larger organizations, such as The International Spina Bifida Association, Samaritan’s Purse and World Vision.

Thanks to the loving, medical care provided by BethanyKids, parents now see their babies in a new and different light: Blessed by God and given an opportunity to live a life of meaning and value. The superstition that babies with SB have been cursed is being dispelled, giving families something we all want for our children: hope.

It’s estimated that more than more than 100,000 new cases of spina bifida occur annually in sub-Saharan Africa, (1) a region where less than 5 percent of the population has access to surgery. (2)

1. *Boston Children’s Hospital, May 1 2014*
2. *The Lancet, British Journal of Medicine, vo.3, no.6 2015*