



Medical feature / CHILDREN'S PROMISE / Summer 1998
(Printable version)

TENDER CARE FOR TINY HEARTS

by Elaine Rogers

In a heart-stopping moment she barely remembers but will never forget, Suzann Cowan recalls the first time she held her newborn son, Christopher Michael, on the morning of March 7, 1993. The euphoric feeling of having brought a new life into the world was quickly displaced by a sense of panic as tight-lipped medical attendants whisked away the infant to initiate emergency care procedures.

"I only got to hold him a few seconds before they took him away," Cowan says of her seven-pound, six ounce baby who was born two weeks head of schedule. "They said he wasn't getting enough oxygen and was turning blue — something about the arteries of his heart being switched the wrong way. It was just such a shock."

Cowan's pregnancy had been normal; even three problem-free sonograms gave no indication of trouble. She and her husband, Michael, both 23 and healthy, had looked forward to their first child's arrival with the usual discussions of nursery decor, maternity leave and sleep deprivation. The young couple from Krum, Texas was completely stunned by their newborn son's diagnosis: cyanotic heart disease — a life-threatening congenital heart defect in which an abnormal cardiovascular system delivers insufficient oxygen to



the body. Nothing had prepared Cowan and her husband for the emotional upheaval of having their baby transported from Denton Regional Medical Center for emergency treatment and heart surgery.

“It wasn’t supposed to be like this,” Cowan remembers “We were in one of those special birthing rooms where you’re supposed to get to spend more time with your baby. And instead, they took him away while I had to stay in the hospital. Before they put him in the ambulance, they brought him by and asked if I wanted to see him. He looked terrible. He was definitely blue by then.”

The Cowan’s pediatrician, Bruce Eckel, M.D., placed a call to the pediatric cardiology team at Cook-Fort Worth Children’s Medical Center. Within hours of his birth, Christopher was being rushed 50 miles to the medical center for further diagnosis and treatment.

“I’ve referred other patients to Cook-Fort Worth and have always had good success,” Eckel says. “I have a good relationship with the cardiologists there. Our patients are well-received and we get good feedback from the doctors. They also have a very fast response time in terms of transporting patients to their facility.”

Christopher’s case called for the skills of cardiovascular surgeon Lawrence Fox, M.D., one of the newest members of the medical center’s staff. Cardiologists allowed the patient to stabilize before Fox performed a surgical procedure called an arterial switch to correct the transposition of the great arteries of the heart. The operation took place when Christopher was three days old and was a success; his recovery was speedy and he was released to his parents’ care five days later.

“At the time, it seemed like the longest week of my life,” Cowan recalls. “But, it really is incredible that he came home so soon and he’s doing so great. In the olden days, I know I wouldn’t have been able to say that.”

Christopher is now a happy, healthy baby whose only sign of his tremendous ordeal is a four-inch scar on his chest. “He’s very strong,” the proud mom says. “He lifted his head right after his recovery. Now he’s smiling quite a bit and likes to hold your hands and try to pull himself up.”

Eckel adds his professional appreciation for Christopher’s outcome. “To have major surgery,” says the Denton pediatrician, “and be well enough to go home in a week like that is just astounding to me.”

The happy ending to Christopher’s story parallels a new beginning for the medical center’s pediatric cardiology program and recent recognition as a regional center of excellence for the care and treatment of children with heart problems. Fox’s arrival at the medical center last fall signaled an expanded commitment to the program and he performed 139 pediatric heart surgeries during his first seven months on staff.

“We’re doing twice the volume of heart operations this hospital has ever done and our growth is exponential,” Fox says. He explains that the department’s surgical load is likely to increase by more than 400 heart surgeries per year in the next few years, although he stresses that volume is not of primary importance.

“We believe that every child we take care of should be treated like one of our own,” he says, “so we do whatever it takes to make that happen.

“It takes an enormous amount of institutional commitment to make these sick babies survive these types of operations. While I’m the surgeon, none of this would work if it were dependent on my individual effort. It only works because we have a very large and competent team of anesthesiologists, perfusionists (heart-lung machine technologists), nurses, intensivists, cardiologists and the like.

Advances in knowledge and technology have been major factors in the medical center’s ability to provide this service. These advances make surgery possible on increasingly smaller infants with expectations for even more successful outcomes.

“We are seeing more cardiac patients who need surgery,” says Nancy Cychol, vice president of the nursing services, “and their stays in the hospital are for increasingly shorter lengths of time. That is obviously much better for the children, and it has a lot to do with Dr. Fox’s skill in the operating room.”

Gradually, the medical center is increasing the types of corrective cardiac surgeries performed. In January, the medical center began accepting patients with hypoplastic left heart syndrome, a congenital heart anomaly resulting in an underdeveloped or nonexistent left chamber that is supposed to pump blood to the body. Treatment is complex in that it typically involves three stages of surgery: an initial operation in the first week following birth, another between six and seven months of age, and a final one prior to the second birthday.

Timothy Judge, born March 20th to Stacey McChesney and Jeremy Judge of Merkel, Texas, became a recent beneficiary of the life-saving procedure after doctors at Hendricks Medical Center in Abilene suspected the problem and contacted Cook-Fort Worth Children’s Medical Center. Timothy and his mother were flown via the medical center’s Teddy Bear Air ambulance to Fort Worth, where he had his first hypoplastic left heart syndrome surgery one week later.

“Everybody says he’s my miracle baby,” McChesney says of Timothy. “Initially, we were informed that he would probably live two week and die. Then, we didn’t even know if he would make it to Cook. He was on 100 percent oxygen and a respirator on the plane. Timmy only had a 30 percent chance of surviving the first operation and he came through it with no complications. So I just have to be thankful of every day I have with him.”

Fox points out the geography as well as knowledge and technology, sometimes plays a part in an infant’s fight against congenital heart disease.

“There are still places in the country,” the surgeon says, “where parents of babies with these conditions are told that nothing can be done and the babies just die.” Some hospitals, he adds, are reluctant to permit surgeries on infants with congenital heart defects because of historically high mortality rates.

This is especially significant when, as medical director Eugene Luckstead, M.D., points out, one in 100 babies born has a congenital heart defect. As a pediatric cardiologist, Luckstead says 75 percent of the heart surgeries performed at the medical center involve children in their first year of life. Of those patients, 25 percent are less than a month old.

A newborn patient with suspected or confirmed heart disease will be placed in the medical center's sophisticated Level III neonatal intensive care unit (NICU). There, a team of pediatric cardiologists and neonatologists perform tests and provide diagnosis. If corrective surgery is prescribed, the patient's condition is stabilized, and then surgery is scheduled.

The tiny patient's family is kept involved and informed throughout the process. Family members are given tours of the operating room and the intensive care facilities, and they are introduced to each nurse who will help care for their child. In addition to the cardiologist and the surgeon who check on the patient daily, pediatric intensivists and primary nurses manage the infant's treatment.

"All the doctors and nurses we dealt with were wonderful and excellent," McChesney recalls. "Everybody was very supportive and helpful, but they didn't give us false hope. They were upfront and honest about telling us the chances of survival. Dr. Fox was especially great. He told us all the risks, but we knew he was our only hope and we knew he was giving Timmy his best effort."

After surgery, heart patients are taken to the pediatric intensive care unit to be closely monitored by a group of nurses who specialize in caring for post-operative heart patients. Later, older infants are transferred to a surgical floor, but newborns return to NICU. Before leaving the hospital, parents have the opportunity to spend at least one night with their baby in special parenting rooms where they can get to know the infant and learn how to tend to special care needs he or she may have.

"Most of our newborn heart patients come to us straight from another hospital," explains NICU director Barbara Greer, RN, "so the parents haven't had a chance to spend any time with their baby — to love on them or get used to them.

"Because of that," Greer continues, "our neonatal nurses do a lot of education and problem-solving with the parents to make sure they know how to feed their babies and they're comfortable with any medications or special equipment they may have to take home with them. We teach all of our parents how to do CPR (cardiopulmonary resuscitation), we help them with any breast feeding problems they may have, and we teach them about car seat safety and taking temperatures."

In addition to the state-of-the-art medical treatment and personalized care, heart patients and their families often also require emotional support, counseling and problem-solving help. The medical center's social services staff and patient representative personnel are ready to help. Issues addressed may range from simple parking problems to more complex financial questions or even grief counseling.

"It's everybody's input together as a team that makes it all work," Fox reiterates. "It's a commitment to the total care of babies and children who have heart disease."

