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The twins decision, Part 2

Now one fights for her life

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Baby Girl B, the Siamese twin separated from her sister five weeks earlier, looked strong and healthy as she lay in the crib in the pediatric intensive care unit.

She sucked on pacifiers, was alert and moved about easily despite the abnormally large reconstructed chest, which had been attached to her sister.

But somewhere in the tiny body of Baby Girl B was a potentially lethal pocket of infection that had refused to respond to antibiotics. It was essential to find out where the infection was before it broke loose and overwhelmed the helpless baby.

Surgery was the only way to do this now, but the surgeons were afraid that the stress of another operation would tip the fragile balance of life and kill the baby.

It was one of those tightropes that physicians so often must walk.

The threat of infection was only the latest in a series of crises that the sturdy little twin had confronted in the 37 days since she had been separated from her sister, who died in the operation. In that time her kidneys had stopped making urine. Biochemical problems developed that could throw her into convulsions, cause a brain hemorrhage or rob her of energy.

And for a few minutes her heart stopped.

Each time the doctors at Children's Hospital had responded quickly and forcefully. Dialysis was used to clear her body of the toxic wastes created by the kidney problem. Biochemical supplements and blood transfusions were pumped into her body. And electricity and drugs jolted her heart back to a steady beat.

Now, Dr. C. Everett Koop, the chief of surgery at Children's Hospital and the man who had separated

(See BABY on 14-A)

'Miracle baby': The fight for life

BABY, From 1-A

the twins, was concerned and saddened by the growing evidence that the child had an infection.

Never before had a Siamese twin with Baby Girl B's type of problem survived an operation more than 11 hours. She and her sister had been joined at the chest; they had shared a liver and a heart and a half. The surgeons had had to sacrifice the other girl, Baby Girl A, because the fused heart was not strong enough to support two babies, but they had hoped that Baby Girl B might survive, despite the vast odds against her.

(The family has asked to remain anonymous.)

For a while it looked as though the sturdy little baby was overcoming those odds, but then the laboratory figures got worse and worse.

The daily tests indicated that the levels of hemoglobin and platelets, needed for clotting, were low, and other blood factors also were abnormal. An infection was lurking somewhere.

Also, her bilirubin levels were high. Bilirubin is the biochemical that the liver makes in getting rid of worn-out red cells. Excess amounts of this substance indicate liver trouble.

Dr. Koop and his chief assistant, Dr. Louise Schnauffer, had to decide what to do quickly, because all these things constituted a severe risk to the child.

To operate was a risk, but not to operate was a bigger risk. After meeting with consultants Thursday morning, Dr. Koop decided to go ahead with the surgery.

An abscess seemed likely, since it would account for the high levels of bilirubin as well as the low levels of platelets and hemoglobin. It would show up as a spongy bump on the usually smooth liver and then it could be easily drained.

The operation probably would take no more than a half hour.

It was scheduled for Friday afternoon.

Baby Girl B was coming to be known as a miracle baby at Children's, because she kept overcoming one crisis after another against all probability.

The first crisis had come only hours after her operation, while she was recovering from the anesthetic.

She stopped making urine. This was very ominous, because in such a small baby the toxic wastes could build to lethal levels in only 48 hours.

Dr. Michael E. Norman, a kidney specialist, was called. Extra fluids were given to flush out the kidneys and, as an added precaution, the wastes were cleared artificially with dialysis.

Two days later, more trouble developed. Lab studies showed a drop in Baby Girl B's calcium and blood sugar. Calcium deficiencies can cause convulsions and low blood sugar can lead to serious weakness. Supplements were given, but only a slight improvement was noted.

And the 11 monitoring and fluid lines going into her body posed a constant threat of infection. The doctors began giving her three antibiotics, and by Oct. 14 her signs had improved.

But then on Oct. 17 the microbiologists discovered *Pseudomonas* in the girl's throat.

This is a common bacteria that does not usually cause problems but that can be lethal in a seriously weakened patient.

The bad news about the *Pseudomonas*, however, was offset by the fact that the calcium and glucose levels in Baby Girl B's blood were beginning to stabilize.

Clearly infection was the big thing to worry about.

The baby was fortified with extra platelets, fresh plasma and packed red cells. The improvement was only temporary, but the child appeared healthy and there were no outward signs of infection.

She started eating, and on Oct. 22 the anesthesiologist tried to take her

off the ventilator that had been breathing for her. But her lungs, weakened by the surgery that had separated her lungs from her sister's, could not function unassisted and she had to be put back on the machine.

Still she seemed to be doing fairly well otherwise.

But then on Oct. 28 her heart stopped.

It happened at 11:30 p.m. when she vomited and clogged the tube that had been giving her oxygen. Doctors and nurses swarmed over her. They shocked her still heart with electricity to get it beating steadily. They gave her drugs. Dr. Ruby Godenness, an anesthesiologist, massaged her heart with his hands.

Again the sturdy little baby pulled through.

On Oct. 29, the day after the cardiac arrest, Dr. Holzer wrote in the chart:

"The patient looks much better but continues to have low urine output. She has good pulses and appears essentially unchanged from the pre-arrest state."

But there was also bad news on this day.

The bilirubin shot up to very high levels and the platelets started to plunge. As this happened, the child started to turn a brilliant orange, indicating severe jaundice.

Hematologist Dr. Charles S. August was called in. They discussed the possibility of taking out all her blood and replacing it with fresh blood that had a lot of platelets and low bilirubin levels. But such exchange transfusions pose risks so this was put off.

By Nov. 10 it was clear that it would be weeks if not months before the baby could be weaned off the breathing machine.

And it is dangerous to keep a breathing tube in a patient's throat for more than a month.

They would have to operate and open a hole in the baby's throat. This could pose another threat of infection, but at least the vocal cords would not be hurt by the tube.

The surgery was done without problems. At the same time the doctors cleaned up the old surgical wound, which had some bacteria in it, and hoped this might clear up the mysterious infection.

But it did not work, and by late last week the surgeons were confronted with the problem of what to do next.

Baby Girl B lay on the operating table, her huge chest and belly grotesquely distorted by the fluids that had been building up in her abdominal cavity, probably the result of the problem associated with her liver.

Dr. Koop made the incision at 4:05, cutting open a hole about two inches across. Sticking a suction device into the hole, he drained out about two cups of reddish fluid, a huge amount considering the small size of the baby (she was not much bigger than two footballs).

Then he put his finger into the hole and felt the surface of the liver, looking for the spongy abscess. He could find nothing.

The liver felt particularly firm, a bad sign, indicating that it was badly scarred. This might be irreversible if it were too far advanced.

He cut out a wedge of liver, about the size of a finger tip, for the pathologist to examine. The liver did not bleed much, another bad sign. This was another indication of cirrhosis.

Dr. Koop and Dr. Schnauffer looked sad. They had hoped so much that the exploratory work would turn up an abscess and solve the mystery.

But instead of that they discovered what could be a very serious and possibly irreversible problem.

Over the weekend the biopsy specimen would be prepared and on Monday the pathologists would look at it under the microscope and do other tricks to learn the secrets the tissue might contain.

Until then the other doctors could only support the child and hope that the miracle baby was aptly named.