Philadelphia Anguirer

Philadelphia Inquirer

Thursday, January 12; 1978



Special to The Inquirer / ED ECKSTEIN, Children's Hospital

Surgeons bend over the twins during the separation operation

The Twins Decision

Baby B's

final crisis

By Donald C. Drake Inquirer Medical Writer

Baby Girl B, the Siamese twin who had been given a chance to live because of a dramatic operation, died yesterday at Children's Hospital despite desperate attempts to save her.

The baby's death came 92 days after surgeons separated her from her sister, Baby Girl A, whom surgeons purposely let die during the operation so that Baby girl B might live.

At birth four-months ago, the two girls had shared only 11/2 hearts, which at best were strong enough to support only one of them. It was not the abnormal heart that eventually killed Baby Girl B, but liver trouble and an infection that doctors could not stop—not even with the strongest antibiotics. This is the story of the efforts to keep her alive after the operation Oct. 11.

All along, doctors had feared that the abnormal heart could not survive surgery. The thought had been that the heart might stop the minute they cut the second child from her sister, Or, if she survived that part of the procedure, that the heart could not continue functioning since it was so abnormal.

But the heart did remarkably well. (See TWIN on 4-A)



A saddened Dr. Louise Schnaufer describes the efforts to save the child



Special to The Inquirer / ED ECKSTEIN, Children's Hospital

The hospital surgical team had hundreds of tools on hand during the lengthy operation to separate the two baby girls

# The last crisis of Baby Girl B

#### TWIN, From 1-A

Even as recently as a week ago, Dr. Paul Weinberg, the cardiologist for Baby Girl B—all family names have been withheld to protect their privacy — had said that everything looked fine.

The heart, with six instead of the normal four chambers, was beating forcefully and in proper rhythm.

Dr. Weinberg said it was impossible to say how the extra two chambers — from Baby Girl A — were faring. But the abnormality was not interfering with the functioning of the heart.

But strong heart or not, Baby Girl B encountered one crisis after another. She repeatedly became infected because she had been made so vulnerable by her weakened condition and the many insertions of tubes into her body.

At one time she suffered a cardiac arrest when she breathed in, or aspirated, her food, but emergency measures pulled her through.

 The clotting factors in her blood periodically dropped to low levels. threatening internal bleeding or a brain hemorrhage.

The nursing care was intense. At first a nurse was assigned solely to her, around the clock, three shifts a day.

Every three hours nurses would vibrate her chest and use suction devices to clear her windpipe to keep it free of fluids. They would also check the ventilator that was breathing for her and make sure that the intravenous lines and arterial lines and feeding tubes were clear.

The overhead warmer was monitored constantly to make sure that her skin temperature always stayed at 36.5 degrees centigrade (97.7 Fahrenheit).

Drugs, fluids and other supplements were given to keep in proper balance the constantly changing biochemical levels of her body.

### A bad sign

She seemed strong and alert, and for some time it seemed that the medical team was pulling her through. But despite everything done for her, one ominous reading remained dangerously high. This was the level of bilirubin, a biochemical made from worn-out blood cells that the body normally disposes of. That she had too much bilirubin could mean only one thing: Baby Girl B's liver was not functioning properly.

The doctors had not expected problems with the liver. The sisters had shared a fused liver as well as a heart, but the livers are comparatively easy to divide in Siamese twin separations.

On two occasions after the separation, the surgeons took biopsies, or samples, of the liver to see whether Baby Girl B's was badly diseased or damaged.

The pathologists were shocked by what they saw under the microscope on both occasions.

Looking at samples taken from three different parts of the liver, Dr. C. L. Witzleben, chief pathologist, could find no normal liver cells. Judging from the samples, the twin's liver was essentially dead. And without a liver, the child would be dead within 24 hours.

The surgeons later determined that they must have inadvertently taken samples from the scar site where the liver had been separated from Baby Girl A's during the surgery. But in any event, something was decidedly wrong.

Dr. Philip G. Holtzapple, a liver specialist, was summoned.

#### Functioning

Tests indicated that the liver was still performing the functions on which Baby Girl B's life depended. It was still releasing glucose needed for energy, it was still making the substances that prevent internal hemorrhages, and it was cleaning the blood of toxins such as ammonia from the intestines.

But in liver disease, these functions are the last to cease. The continued high bilirubin level indicated that the liver was being destroyed more every day.

By last week Dr. Holtzapple held out little hope. The destructive process had been going on too long.

At best, Baby Girl B had only a few years to live. At worst, death could come suddenly. One of the questions that had been raised was whether the physicians should try to resuscitate the baby if she had another cardiac arrest.

If she had no future, why subject her and her parents to the trauma of life-saving attempts that at best would put off death by only a few weeks or months?

But on the basis of the biopsies, Dr. Holtzapple could not be absolutely certain. He could not put a figure on the child's chances; certainly they were less than 10 percent, probably much less.

The doctors therefore felt that they could do nothing less than everything to save Baby Girl B should her heart suddenly stop.

### Beginning of the end

The firt sign that the end was beginning for Baby Girl B came Monday when doctors and nurses noticed a swelling around her eyes.

She became listless and lost interest in the pacifier she had been sucking on. The acidic level on her blood went up.

The acidic levels got worse the next day, and on Tuesday the platelets, clotting factors in her blood, began to drop.

This was strongly indicative of an infection coursing through her blood. Antibiotics were pumped by intravenous line directly into her blood.

But they were for naught.

The liver disease and the tubes into her body had left her too vulnerable, and the infection could not be stopped.

Her heart stopped at 2 a.m. yesterday.

## Emergency call

The nurse on duty immediately detected this, and an emergency call for help was sounded. A dozen doctors and nurses swarmed into Room 4016 — one of the six pediatric intensive-care isolation units.

Under the direction of Dr. Colette O'Keeffe, the anesthesiologist on duty, and Dr. W. Clark Hargrove, the surgeon, the quickly assembled team struggled to restart the heart.

The drugs atropine and epinephrine were injected into her circulation to make her heart beat faster and with more force.

Sodium bicarbonate was given to counteract the acid that was building up in her blood — a lethal waste product of oxygen-starved cells that were dying.

Calcium was given to help the heart.

Baby Girl B's heart rate, which, should have been 110, slowly climbed from 50 to 100 as the drugs took effect.

But then down it went again, to 30 this time.

More atropine, calcium, spinephrine were injected. Dr. O'Keeffe pressed down hard on the baby's chest, squeezing the stilled heart between the bones of the chest and mechanically forcing the blood to circulate.

The heart rate went up again but only to 90 this time.

This process was repeated again and again. Each time the heart responded less effectively.

Dr. C. Everett Koop, chief of surgery at Children's and the baby's primary physician, was on vacation in Texas. But his assistant, Dr. Louise Schnaufer, related the anxious developments by telephone.

His orders to her were to continue the resuscitation attempt even though the responses were becoming negligible.

Finally, a little before 4, two hours after the heart had stopped, the doctors could get no response with any of their drugs.

Baby Girl B was declared dead at 4:04 a.m.

Doctors will never know why the liver failed. The parents, Orthodox, Jews, refused to permit an autopsy.

Rabbi M. D. Tendler, an authority on Jewish law, had advised the parents, who called him yesterday morning, that an autopsy would be permissible in such a case as this.

In fact, he said, there was a religious obligation since such an autopsy would not be a "fishing trip" but something that might help prevent similar deaths in the future.

But Baby Girl B's grandfather, himself a rabbi, felt differently, and the family declined.

Why did Baby Girl B die?

Yesterday, Rabbi Tendler attempted an answer:

"This big question of why do the tests of humility and faith — humility because we don't have a handle to analyze it and faith that there is a master scheme for the world.

"One thing we can be certain of—it was not an act of randomness. It was not an act of arbitrariness. There must be a scheme to this if you have any concept of God as being an omniscient being . . . a rational being and not a fellow standing up there and playing games, amusing himself at our expense. There must be a rationals to all of this."