

## Life's tiny miracles

Lara Becker

Children's Hospital at Strong gives pint-size patients a fighting chance in daily battle against odds.

WRITTEN BY LARA BECKER STAFF WRITER PHOTOGRAPHED BY WILL YURMAN STAFF PHOTOGRAPHER

For 16 years, Robert Sinkin has zipped on a well-worn Santa suit, stuffed his waistline with padding and posed with babies too sick or too small to sit on his lap, let alone leave the hospital in time for Christmas.

Sinkin is an unlikely Santa. He's the medical director of the neonatal intensive care unit of Children's Hospital at Strong, a lanky guy with an unmistakable Long Island accent. And he's Jewish.

“I'm into the holiday spirit, of course,” Sinkin said. “I just don't believe in Christmas.”

Not in a religious sense, anyway. But if Christmas is the celebration of a miraculous birth, then every day is Christmas in the neonatal unit.

Half of the 1,200 babies admitted here annually were born prematurely. They are dwarfed by the Beanie Babies lining their beds, and they battle massive health problems: lung disease, heart failure, brain hemorrhages. The other half were born full-term but may have complications as severe as Down syndrome, spina bifida or abdominal wall defects that cause the intestines and liver to hang outside the body.

Their survival is a miracle - and modern medicine alone doesn't always explain it.

Summer Farmen, for example, believes her 3-day-old baby died so that his twin brother could live.

Gage was, after all, the more robust of the two babies, delivered four months before they were due. But after Gage died on Oct. 27, from a

combination of pulmonary hemorrhage, pneumonia, extreme prematurity and infection, his brother Jackson began to thrive.

Though his struggle is far from over (no preemie is considered out of danger until his due date nears), Jackson has successfully endured open-heart surgery, a procedure Sinkin likens to ``fixing the plumbing."

He has tolerated the insertion, removal and re-insertion of feeding, breathing and intravenous tubes. He has doubled his birth weight - a little more than one pound - and recently had his first bowel movement, a sign that his digestive system is working, and an event Farmen felt worthy of an entry in her journal.

He has developed an attitude, too, pushing himself with doll-sized hands into new positions and twisting his head to loosen the tangle of tubes that cover his tiny face. He's so active, in fact, that the nurses have had to sedate him to ensure he doesn't get exhausted, or worse, disconnected.

Still, the next milestone - Jackson's first Christmas - will pass like the rest: in the 88-degree confines of his glass-topped isolette.

#### Medical miracles

If the neonatal unit were a Hollywood set, it would resemble something from Star Trek. Visitors walk through glass double doors that open with the touch of a button.

Phototherapy lamps, used to combat the effects of jaundice, cast a bluish light over rows of isolettes in eight connected rooms called pods. Doctors and nurses stand in clusters, observing patients, taking notes and constantly adjusting controls.

This is a laboratory, of sorts, and as such there is always a lot of experimenting going on. Early trials of a revolutionary drug called surfactant - produced naturally in healthy lungs to keep airways open but often lacking in the immature lungs of premature babies - were conducted in the neonatal unit.

At the time, about 16 years ago, surfactant was extracted mainly from calf lungs. The neonatal doctors were never in short supply: Sinkin recalled they would make runs to a nearby meat market for more, rinse them out and distill their coveted contents into usable form.

Over the last five years, surfactant has halved the infant mortality rate from 8 to 4 per 1,000 babies. New technology, available at Children's Hospital at Strong, has also contributed to those vastly improved results, including humidified incubators and ventilators specially designed for babies' fragile lungs.

Suffice it to say, this is not an atmosphere conducive to anything as festive as a Christmas tree (or a menorah; flames from the candles would cause the pure oxygen to ignite). But the neonatal unit is not devoid of spirit.

There is, either by nature or by necessity, a feeling of camaraderie about the place, simply because the parents there face a similar plight.

``Every family is in crisis," Sinkin said.

For that reason, there is a veritable army of people around to help: 10 neonatologists, six medical school fellows, nine nurse practitioners, two social workers, any number of pediatric residents and 180 staff nurses. They are divided into two teams - blue and gold - and dispersed throughout the neonatal unit.

Doctors receive special training in delivering bad news and best possible outcomes, which is not always that the baby will go home. Few in the neonatal unit are spared the ethical, and sometimes legal, dilemmas that come from trying to save such acutely ill babies.

``It's never, `This is routine, take a number, I'll see you tomorrow,'" Sinkin said.

A sad sacrifice

The nurses, especially, become close with the patients as well as their anxious parents, and Farmen is one of their favorites. It's easy to see why: Despite the pain of losing one son and the struggle of keeping another alive, 24-year-old Farmen of Fairport is remarkably ebullient.

A petite brunette with a charmingly raspy voice, she possesses the enthusiasm of an aerobics instructor (which, in her free time before she became pregnant, she was).

She and her 27-year-old husband, Jeff, straddle the line between realism and optimism masterfully. They take every bit of good news with a grain of salt, including the latest, from a neonatologist: that Jackson is developing at a faster clip than other babies who, at his age, would still be in the womb.

Farmen has become a bit of an expert, having spent more time at her son's bedside than she did at her full-time job as a special education reading teacher in East Rochester. She hated science class but spouts off medical terms like a pro. She records in her journal Jackson's medicine, food and oxygen intake the way most parents keep track of their baby's first steps.

The only blank pages are from the days when she was first brought to Strong Memorial Hospital with labor pains - an episode that still sends her into tears.

Just 24 weeks pregnant, Farmen had yet to take Lamaze classes. She relied instead on breathing techniques she learned in a Yoga class.

But nothing could have prepared her for the pain of Gage's death. It has ebbed with time, though in her journal she refers to it as the ``most horrible experience of my life."

In the beginning, grief overcame her daily. ``It used to be when I was blow-drying my hair, or during quiet time in the shower," Farmen said. Now she's come to think of his passing as a bittersweet blessing, a sad sacrifice.

### Silent nights

Amid the white noise of the neonatal unit - the soft whisper of ventilators, the staccato beeping of heart monitors, the more sustained notes of alarm bells - there is the occasional sound of a baby crying. But that is rare.

The endotracheal tubes that allow the babies to breathe press against their vocal chords and keep them from vibrating. So, they open their mouths, scrunch their faces, turn purple from the effort - and emit what's known as ``the silent cry."

After 62 days, a silent cry is still all Jackson is capable of.

When he arrived in the neonatal unit, he had a 5-percent chance of survival. It rose to 45 percent in the second week, and after that, Farmen said, ``I never asked."

But his caretakers say he's doing well.

During an ultrasound examination last week, a nurse casually made reference to the day Jackson would leave the hospital. Farmen ran to the phone to call her husband.

``They used the word discharge!" she said. ``They actually used the word discharge!"

It was a well-timed gift: For Christmas, Farmen and her family finally have hope.