

A Little Joy

Chapter One

The telephone's insistent ringing broke through the noise of my children's chatter. The butterflies in my stomach quivered. I'd been waiting for that phone to ring. I was anxious to hear Dr. Shonk's verdict, but I dreaded what I might learn.

Our family doctor sounded urgent. "Mrs. Biehn, I've talked to Dr. Clark, a pediatric surgeon at McMaster University Medical Center. Your baby's ultrasound shows a mass in her abdomen—possibly a tumor. Can you take Sarah Joy to the medical center in Hamilton tomorrow? She'll need some further tests." Doctor Shonk gave me directions to the hospital in Hamilton, Ontario, an hour's drive away. "And, Mrs. Biehn," he finished, "pack your toothbrush. I wish you well."

I hung up the phone, the doctor's words ringing in my mind. *Pack your toothbrush.* That meant we'd be staying awhile. The butterflies in my stomach tumbled into a knot. Were my fears coming true? What was ahead for my Sarah Joy? I gazed fondly at my five-month-old daughter. She was her usual cheerful little self, smiling at the antics of her big sister Justina and brother Philip playing nearby. Nothing looked out of the ordinary.

My husband Roy and I had looked forward to the arrival of our third child. We were both very fond of children. Three-year-old Philip and five-year-old Justina were both old enough to look forward to a new baby too.

Contrary to what I'd been told—that third babies often arrive quickly—Sarah Joy had taken her time about arriving. Although my pregnancy had been normal, a small apprehension stirred while we waited. Justina had been a normal-sized newborn, but Philip, born with Bloom's Syndrome¹, had weighed less than five pounds. Tiny Sarah, like her brother Philip, was also born with this syndrome. However, despite Philip's smallness, he had passed the usual milestones at appropriate times.

On the day of Sarah's birth, Roy and I had settled into a new birthing room at the Kitchener-Waterloo Hospital. The birth proceeded naturally with Dr. Shonk in attendance.

Our little "bundle of joy" arrived at twelve minutes after midnight on April 8, 1982. She cried only a little, but it was a healthy-sounding cry. The nurse and doctor cared for the baby and then I eagerly held out my arms and snuggled her close. "Oh, she's so sweet and so tiny!" I exclaimed.

"Yes, she's very small. She weighs only four pounds and two ounces," offered the nurse. "And she's just seventeen inches long."

"Even though she's tiny, she seems to be full-term," Dr. Shonk said. "She has no problem with respiration."

"Look, Roy," I said, "a little bit of brown hair and deep blue eyes."

"I think those eyes will turn brown like the rest of ours," Roy replied.

"I think we'd better keep her warm," advised Dr. Shonk. "Because she's so small, she'll lose body heat quickly."

We named our baby Sarah Joy, and the name fit her well. Little did we know what joy and also what sadness were to follow her arrival.

¹ Bloom's Syndrome is a rare inherited genetic disorder that is autosomal and recessive. It is characterized by low birth weight and continued small stature. Symptoms include sun sensitivity, butterfly-shaped facial rash, increased susceptibility to infections and respiratory disease, and predisposition to cancers and leukemia.

Sarah Joy was a contented newborn. But because she was so tiny, the nurses put a little cap on her head as they did for the premie babies and placed her in an incubator for extra warmth. After a period of observation, I was allowed to have Sarah's incubator in my room. Not only did the incubator keep my baby warm; it also protected her from visitors' germs. As an extra precaution due to Sarah's size, I stayed in the hospital with her for about a week.

By the time Roy and I took Sarah Joy home, she was gaining weight and nursing well. I savored the moments with my wee baby. April in Ontario can still be chilly. Sarah needed lots of clothes and blankets to keep her warm. I often dressed her in tiny sleepers with hoods, followed by a cozy blanket. Sarah was an especially cuddly baby who loved being held. I was hopelessly in love with her, as I had been with all of my babies.

Philip and Justina, too, loved their little sister. They were big enough to run errands and help care for her. They liked to hold Sarah Joy, and she smiled and responded to their chatter.

Justina's boundless energy came in handy when I worked in my garden later that spring. "Justina," I'd call, "please run and see if Sarah is awake yet." Justina's dark brown eyes would sparkle as she'd scamper to the house to check on the baby.

Philip's fair skin and straight red hair contrasted with Justina's dark brown curls. He was petite, but what he lacked in size, he made up for in energy. "Mommy, can I hold Sarah?" he'd ask. Then he'd hop up on the couch and open his arms wide. His baby sister was just the right size for him.

At the time of Sarah's birth, we lived in a big old rented house on a pig farm with an open manure pit behind the barn. Since Roy and I had both grown up on farms, the smell didn't bother us very much.

Nor did it bother Philip. In fact, he loved those smelly pigs. Many days he'd beg, "I want to go see the pigs, Mommy." The pigs didn't belong to us, but the kindly neighbor who owned them didn't mind us visiting the pig barn. So I'd take little Philip by the hand, and off we'd go on a pilgrimage to the barn. Later we'd emerge smelling like the pigs we'd left behind.

Philip was a great inventor. He created many things using cardboard, scissors, and tape. He found uses for small motors and batteries. Roy, who also liked making things, encouraged his little boy.

Our household was busy with two young children plus a baby to feed at night. I needed plenty of rest. Sometimes during the day I'd lie on the couch and snuggle tiny Sarah up over my shoulder. Even if she was awake she was satisfied just to be held. She'd lie there contentedly while I caught a few moments of shut-eye.

That summer we planted a large vegetable garden. When I found my days too full, we got Donna, a teenage friend of our family, to help us. The garden grew and the children grew, and even little Sarah grew nicely, so that by September she was double her birth weight. At two months she weathered chicken pox. No one was alarmed that she got the sniffles more easily than the other two children.

I noticed that Sarah tended to spit up her food more than Justina and Philip had, but I only figured it was my turn to have a "spitty" baby. It was a minor laundry problem—surely nothing to be concerned about. As she grew older, however, she seemed to spit up even more. I was to learn that in Sarah's case this was reason for concern.

What's Wrong With My Baby?

Chapter Two

In September Justina turned six years old and started off to Countryside Christian School. She rode to school in Great-Uncle Oliver's car with some other children. Uncle Oliver was jolly and the children enjoyed the ride. Roy and I were glad for this convenience.

One night our contented five-month-old Sarah was unusually fussy. In the dark of the night, as I cared for her, I noticed that her tummy seemed quite firm. When Roy also awoke, I got him to feel Sarah's tummy too. "Does her tummy feel normal?" I asked. "It seems firm instead of soft on this side." We decided it was probably just gas, and that sometimes things seemed worse in the middle of the night. After all, I wasn't a first-time mother and I didn't want to overreact. Soon we were all fast asleep again.

The next morning Sarah was her smiley happy self. *Probably*, I thought, *her tummy had just been a little upset*. However, when I checked again, her tummy still seemed firm on one side. My concern grew. The next day I met my aunt Elsie, an experienced nurse. "Aunt Elsie," I said, "could you please feel Sarah's tummy?" She did so carefully. "Is it normal," I asked, "or do you feel something?"

"It does feel rather firm," Aunt Elsie replied. "You'd better get her checked."