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JOHANNA WAS A SUN SHOWER

BY KAREN KENYON
SAN DIEGO, CALIFORNIA

It was hard for me to care for Johanna at first; I felt like cringing or hiding. Why did this happen to us? I kept asking. But then I began to see what she really was: a little baby girl who needed me—and a very precious gift I almost didn't recognize

Johanna was born three days before Christmas. It all seemed too good to be true—we had a baby girl and she looked fine. She weighed a robust nine pounds five ounces. She had all her fingers and toes. She had black hair like Dick's.

In the recovery room I thought about how much I had wanted this baby, how much trouble I had had conceiving her. Nine months before we had almost completed an adoption, but had canceled it when we discovered we were going to have a second child of our own after all.

And I thought about how much I had changed in the last year—how I had discovered more about myself. I had discovered that having a baby did not have to be all there was to me. The joy of giving birth was a very good, beautiful part of life, but now I would have even more to give this baby—and myself and my husband and Richard, our four-year-old son—because I was finding the joy of my own self; and this little baby was part of my new beginning.

The hospital pediatrician came into the recovery room to see me. She asked me my age and wanted to know whether I had had any problems during this or any other pregnancy. She looked a little strained, and I searched her face in vain for that pleased, proud look all people involved in a birth usually have. Maybe she is tired, I thought. Or maybe she is so used to babies' being born that she has little feeling for the individual mother and child. It's okay, I thought; I've had a beautiful baby girl. And I remembered that the obstetrician had smiled and congratulated me.

When the nurse came to wheel me to my room, I asked to see my baby on the way. Because she had a slight breathing problem immediately after birth, I had been told that she'd be placed in an isolette. She was there now when I went by, as the doctors had said.

Back in my room, both Dick and I were filled with happy thoughts of our daughter. We pictured her in two years or so, a little girl with long black hair, running and playing. She must have a very pretty name, we thought. We chose Johanna Leigh. Johanna with the long black hair. Richard's little sister.

We were filled with joy that day. Dick made many happy phone calls, shared a toast to Johanna with friends and told Richie he had a new baby sister and he would see her, and Mom too, soon.

But as each feedingtime came around I began to yearn for my baby daughter. And each time I was informed that they would bring her tomorrow—she needed the isolette today. Again I searched the faces of the nurses for that excitement and joy new life brings. "Is this your only child?" they would say. "Oh, how nice that you already have a healthy boy!" They seemed to be trying to soothe me with small talk. Why?

The next morning I walked to the nursery to see her. I wanted so to touch her, to hold her. No. I was informed she couldn't come out until the doctor had seen me. Why? What could be wrong?

When my obstetrician came in, I asked him about the baby. "The pediatrician is a little concerned," he said, "but let's not worry until she has finished her diagnosis."

After he left I couldn't hold back my tears. I called Dick.

"Can you come?" I said. "I'm afraid. There might be something wrong."

Half an hour later he was at the hospital. And shortly afterward the pediatrician arrived.

"Mrs. Kenyon, your baby no longer has a breathing problem," she said, "so she is all right in that respect. However, we have completed some tests, and based on them and on my observations, we are fairly sure she is mongoloid."

Fearful silence struck, as if time expanded in rings of fright. This isn't real, I thought. Anxiety raced within me. I could say only, "No, no, it isn't true! Are you sure? No, I can't believe it!" My hands rushed to my face to shut out the sight of this doctor—the reality of what she had said. I shook my head. "This can't be." Dick, sitting in a chair at the foot of my bed, dropped his face into his hands and began to cry.

"Do you want to hold your baby now and feed her?"

They brought Johanna in. But suddenly all the love I had felt for her was

gone. Who was she? What was she? This was not the baby I had expected.

"No, take her away," I said. "I want to go home."

I was released, allowed to go home early. And we were told we could take Johanna home in three days—the day after Christmas.

Once at home depression engulfed me. I called close friends to tell them what had happened. It was a reaching out—almost a hope that someone, somewhere, would say, "No, it's not really true—it didn't really happen."

And in the midst of their holiday festivities our friends came. They let themselves share our sadness and feel our pain. They couldn't heal the wound or fill the deep hole, but they put something new into me. They put love into me. They cared, and I felt close to everyone—completely open and vulnerable in a way I had never been before. I hurt too, as I should have hurt. But now I felt their love, and having love made it easier eventually to give love.

We brought Johanna home on December 26th. The nurses in the hospital seemed too cheery. I wanted to see some reality then. I wanted to hear something besides, "Mrs. Kenyon, she is just fine. She drinks and wets and does everything she is supposed to do." I was still hurt inside. I didn't think everything was just fine.

It was hard for me to care for Johanna those first few days. I felt like cringing; I felt like hiding. So Dick took care of her; he never withheld his love. He felt from the start that she was our little baby, and that if this shouldn't have happened to us, it shouldn't have happened to her either. Later we realized that saying, "This shouldn't have happened to us" didn't make any sense. Really, why shouldn't it have happened to us? Or maybe it was more that it couldn't have happened any other way. Just as, in those first few days, I couldn't have been any other way. I had to get my negative feelings out before my acceptance and love could come in.

A friend of ours, a practicing psychologist, was kind enough to let me call him—encouraged me to call him—any time I needed to those first weeks. That way I was able to talk about my fear and anger and hurt. He never made me feel that I should feel any other way, but he also assured me that things were not really as dark as they seemed to me then. I will always be grateful to him for that.

Dick and I avoided emotional contact with each other that first week. It was as if it was all too much. There could be no leaning on each other. We both, by ourselves, had to come to terms with what had happened.

As the weeks passed I began to look at Johanna and see what I really had. A little baby. A little, pink, soft baby girl who needed me. Not a retarded child with problems I would have to deal with, not a retarded adult who might not fit anywhere, not a child that people would stare at—only a little, soft baby girl. I began to love her for what she was right then. And so I learned another important lesson—all we have is what we have right now. The minute I could see that, I began to live each moment more fully, and my life instantly became far richer.

Our psychologist friend put us in touch with the Association for Parents of Retarded Children, who in turn put us in contact with the Regional Center for Retarded Children. Here we found understanding and help.

One of the doctors explained exactly what mongolism, or Down's syndrome, is and how it can occur. In normal people the chromosome count of each cell is 46; mongoloid children have an extra chromosome, or 47. In a case of translocation, which was the reason for Johanna's mongolism, either the mother or father carries a double chromosome—two chromosomes "stuck together," appearing as one. (In our case, I was the carrier.) If this chromosome is given to the fetus, the baby will have an extra chromosome, as ours did, and be born mongoloid.

A social worker at the center told us about the type of schooling available for Johanna, and explained that there were alternatives if later we felt we were unable to cope with her. She let us know a bit of what to expect.

When Johanna was six weeks old I had a desire to sketch her. I have always liked to draw, and as I began I realized how very much I did love her. To me, drawing someone is a form of love. And I thought how pretty she would have been if she had been normal.

Gradually my feelings began to change from "You aren't the baby I wanted, but I love you in spite of that" to "I love you just the way you are. You are very dear.

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I almost wouldn't have you any other way." I began to realize Johanna would perceive the world differently from the rest of us, but not in an inferior way, necessarily. I began to see what she had rather than what she didn't have.

She was missing her survival mechanisms—she would die if someone did not care for her—but she would not miss feeling love, she would not miss experiencing beautiful flowers, butterflies and joy. Best of all, while she probably would not be a productive person the way we usually define "productive"—hold a job, make a living—she would never do any harm and she would not hate. And as time went on I realized she *was* productive, because she produced and elicited love; and so her life had great value.

I began to see that our friends, the people we cared for, were learning from her too. And I realized that I didn't need to make excuses for her when I took her out. Her features were not obviously mongoloid, so people saw her only as a baby. But part of me kept wanting to say, "Yes, she is cute, isn't she? And she is also mongoloid. But it is okay. We all have handicaps of one kind or another.

"And she has given us more than a normal baby could have. More pain, yes, but also more understanding, more love. She's taught me that there is love that's not based on 'becauses'—because she is pretty, because she is smart, because she feeds my ego, because she fulfills the great American dream of the perfect little family. She has shown me what beauty can be."

So Johanna became a deep part of our lives—a growing experience, a loving experience.

Little Richard loved his sister the way any little boy loves a new baby sister. He understood that she would be slower in her learning, that she was not as healthy as he was, that she would go to a special school, but these facts were not important to him. The only thing he saw that mattered was a little baby whose hands played with his face and who smiled every time he came near.

It seems so sad that often in life, just when we start to grasp things they slip away, and this is the way it was with Johanna. As we began to love her more and more and the road looked wide ahead, it suddenly came to an end.

I've thought about her death a lot since then. It is almost as if, in the six months she was with us, she had given all there was to give and we had learned enough for a lifetime.

She died very suddenly. She left very quietly, like the Little Prince of Antoine de Saint-Exupéry's story. We were at the house of friends. Johanna was asleep in her car bed in their bedroom. When we went in to get her, she was no longer alive. We gave her artificial respiration until the police came and all the way to the hospital in the police car. I remember hearing the police-car radio message—"A baby is not breathing"—and I thought, A baby. Not a baby who is not normal—just "a baby." She was equal then.

At the hospital the doctor worked on her for an hour and a half, but it was too late. Our pediatrician ordered an autopsy. It showed "no apparent cause of death—Sudden Infant Death Syndrome." Johanna's cardiologist said that in all probability her heart, which had breaks in the conductive system, just didn't get the message to beat any more.

Now it sometimes seems almost unreal, like a dream that is all over; like a chapter that is over in my book, in my life—a very short chapter, but the fullest one I've ever known.

To treasure life, to know that no moments will ever be repeated, was the last lesson she taught me. She was a very precious gift I almost didn't recognize. Johanna was a sun shower.

THE END

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