

LOVING LIFE ENOUGH

FEW PARENTS SUFFER THROUGH THE LOSS OF
THREE CHILDREN. MARY MANACHI REFLECTS ON
THE SOURCE OF HER STRENGTH.

By Mary Manachi, West Paterson, New Jersey

We had just cut the watermelons at a Sunday-school picnic and I was laughing at the kids' antics—pretending to play harmonicas as they munched on the sweet pink slices, using the rinds to make big green grins, seeing who could spit seeds the farthest. When I felt the woman's hand on my arm and saw her sympathetic, questioning eyes, I knew what she would say before she even spoke.

"You seem so happy. Really happy. How do you do it after ... after all that's happened to you?"

Again and again people ask me that same question—people who know that Louis and I had three children born with the blood disorder called Cooley's anemia. First Mary Lou, then Rosemary, then George. One after the other, they were born with it, lived with it and died of it.

How can I be happy after all that's happened? Well...

Mary Lou was born in 1955. She was our second child, coming two years after our strong and healthy daughter Ann. At first I had thought Mary Lou's pale skin meant she took after my side of the family. Louis and I are both of Mediterranean descent, but he's the one with the olive complexion. When I took her to the pediatrician for her

three-month's checkup, he asked me to set up an appointment for testing. "She seems to be anemic," he told me.

It didn't sound too bad; lots of people have anemia. But after Mary Lou was tested at Cornell Medical Center in New York City, the doctor called Louis and me in for a consultation.

"I'm sorry to have to tell you this," the doctor said. "Your baby has *thalassemia major*." he explained that this is commonly known as Cooley's anemia, named after the doctor who identified it. A rare genetic blood disorder, it prevents the body from manufacturing hemoglobin, which carries oxygen from the lungs to body tissues and muscles.

"It mainly affects people of Mediterranean heritage," he told us. He also said that Cornell Medical Center was headquarters for the Harold Weill Clinic, which specializes in treating children with blood diseases. Mary Lou would have to go there every two weeks for a blood transfusion.

From then on I drove my daughter into New York City from New Jersey regularly. After a few months she seemed to get used to it. And she had company; 19 other children were being treated there for the same illness.

Louis and I wanted more children, but now we wondered.

"Don't worry," our doctor assured us, "it is rare that this happens in a family twice."

Rosemary was born in 1959. She looked fine—bright-blue eyes and fine brown hair like Mary Lou's. But just to be certain, I took her to the clinic to be examined. The doctors were noncommittal. Weeks went by. One day she would seem perfectly normal, the next her head would

be sweating. The pattern had been the same with Mary Lou. Then, when she was six months old, the doctor gently told me that Rosemary would also need regular blood transfusions.

So now I was driving two little girls into the city. It was easy to see how much Mary Lou and Rosemary depended on the transfusions. As the time for the treatment neared, they tired easily and became irritable. But after their hospital visit—grueling as it was—they seemed fine. In the meantime, Louis and I tried to give our three daughters a normal life, with music lessons, Monopoly games and plenty of family outings.

In 1961 our son, George, was born. We had yearned for a boy and we had been assured that the chances of our having another child with the same affliction were nil.

But from the first moment I held my little boy in my arms, I knew. Deep down, I knew. Soon I was taking George into New York along with two-year-old Rosemary and six-year-old Mary Lou.

Even so, Louis and I were grateful for our four lovely children. The blood transfusions simply became a regular part of our lives, and we went on hoping that a medical breakthrough would make them unnecessary. Meanwhile we were busy with the usual family things—school activities and vacations. The years passed. Then came our shocking discovery.

One morning while I was waiting at the hospital, a mother of one of the other children quietly handed me a clipping from *The New York Times* headlined “Fatal Blood Disorder.” It was about children coming to that very clinic. One sentence blazed out at me: “They usually die before

they are 20 years old.”

I couldn’t believe it. Our doctor had never been that specific. I took the clipping to him. “Is it true?” I asked.

“Yes,” he said, sighing. “I’m afraid it is.”

There were no drugs, no treatments, no known medical help to prevent my children’s death at a young age.

For weeks Louis and I lived in a daze. His reaction was to say little and concentrate on his work as a garment designer. Mine was to cry whenever I was alone.

The children? We couldn’t bring ourselves to discuss it with them, though I knew they were aware of the seriousness of their condition from talking with the other patients during their hospital visits. And then came one of those small moments that can change the way you see things.

I had walked into 11-year-old Rosemary’s room one evening and found her making a jeweled butterfly pin. She was already selling her work at craft shows.

“How beautiful,” I said, as I watched her set a rhinestone.

“Thanks, Mom,” she said. “I’m going to earn all I can for college.”

She was planning on college?

I cleared my throat. “Um...what are you planning to study?”

She looked up, eyes shining. “Nursing, Mom. I want to be like those nice women at the hospital who help me.”

She turned back to her work and I walked slowly out of the room, trying to take it all in. Rosemary was not thinking about death; she was focusing on life.

At Thanksgiving one of her teachers phoned me. The class had been asked to write about what they were most thankful for. The answers were the usual ones about home, parents and food. The teacher's voice trembled. "I thought you would like to hear Rosemary's answer: 'I thank God for my good health.'"

Good health? How could she write that? And then I remembered the other children Rosemary saw on her hospital visits, the ones with amputations or suffering from cancer. But Rosemary could walk...go to school...skip rope.

Rosemary had filled our house with Scripture plaques that she made. In her own room she had hung the one that read "This is the day which the Lord has made, let us rejoice and be glad in it."

That Thanksgiving I looked around me. I saw that our house was not a house of shadows and sorrow; our children filled it with cheerfulness and bustling activity. Mary Lou's piano music rang through the rooms as she practiced for a recital. Rosemary busily made jewelry and plaques. Little George had an extensive rock collection; he was already talking about becoming a geologist. Slowly I began to see that my children, all of them, were rejoicing in life.

On July 4, 1969, Rosemary, then 12, was in the hospital with a minor cardiac problem, a side effect of Cooley's. "You seem better, honey," I said as I leaned down to kiss her good-bye. "I'll be back in the morning."

The telephone rang just after I got home. Rosemary was gone. "Peacefully," the nurse said.

Mary Lou and George had known their lives would be short, but with Rosemary gone they were forced to

face that fact head-on. Mary Lou, four years older than Rosemary, carefully tended her sister's grave. I knew she must have been contemplating her own death. And yet, I watched as she took up the business of her life with a new vitality. She began making the honor roll in high school and was very popular. And she made a suggestion that gave new direction to our lives.

"Mom," she said, "when I told the kids at the clinic about our vacation to the Poconos, most of them said they had never been to a place like that. Could we find a way to take them with us next time?"

"Of course we can," I said, hugging her. Suddenly we had a project. I started organizing a volunteer group to take the other children on trips. We held bake sales and candy sales and raised enough money for an excursion to Mount Airy Lodge in the Poconos. Most of the children had never been together outside the hospital. How wonderful it was to see them laughing and having a good time, away from the sting of needles, transfusions and spinal taps. We found ways to raise funds to see a Broadway play and even to visit Disney World.

In 1973 Mary Lou graduated from high school, a member of the National Honor Society. She had undergone surgery to remove her spleen, so she had worked extra hard for those honors. In the fall, she entered William Paterson College as a fine-arts major. Soon she made the dean's list. She worked part-time in a TV repair shop and her civic activities—everything from collecting for charity to volunteer work—put her in touch with almost everyone in town.

The following year she volunteered to participate in an experimental drug program for the treatment of Cooley's

anemia. It took a lot out of her and she had to be hospitalized for three weeks. “But if it helps other kids, it’s worth it,” she said.

Mary Lou was 19 that Christmas of 1974. In January, our Christmas tree was still standing in the living room. For some reason I just couldn’t take it down.

On January 20 it snowed heavily, keeping all of us home. Mary Lou practiced her piano in the morning, but got very tired. “I think I’ll rest for a while,” she said as she went up to bed. Later I brought her some lunch.

“Oh, this soup is so good!” she exclaimed. Then the light suddenly went out of her eyes and she fell back on her pillow.

Mary Lou’s funeral was one of the largest ever in West Paterson. Louis and I had no idea she had had so many friends. The mayor and the entire city council were there. In the words of the Cooley’s volunteer group member who honored her, she had been “a very special girl who lived and understood life better in her 19 years than most of us could possibly hope to if we lived to be a hundred.”

Later, as a cold rain battered our living room window, I sat alone, thinking about my radiant daughter. Sighing, I leaned back, staring at the wall. In my line of sight were three of the scripture plaques Rosemary had made: “I will never leave thee, nor forsake thee.” “Casting all your care upon him; for he careth for you.” “Do not be anxious about tomorrow.”

The words blurred in my vision, then cleared. I got up immediately and began preparing dinner for my family.

Our oldest daughter, Ann, was involved in her career, and George, a typical teenager, kept our house lively. His

friends came and went and the telephone rang constantly. He dated and had an after-school job at a local restaurant. We continued to take the Cooley's children on trips and have get-togethers.

George graduated from high school and went on to William Paterson, where he threw himself into a full schedule of activities. He continued working part-time at the restaurant, and the summer he was 19 he bought a sports car—shiny black with fire-engine-red trim. It was a young man's dream—and always full of his friends. He kept it in showroom shape.

That's why, on the night of September 20, I knew something was wrong. George came home from a date and after he went to bed I noticed his car had been pulled into the garage at a careless angle. Always before he had aligned it so straight.

The next morning he stayed home from school. "Mom," he said. "I just can't make it. I'm so tired."

Louis and I took him for a long ride that night, knowing the hum and rhythm of the moving car would help him doze off. When we got back to the house, he sank down on the couch. "I know I'm going, Mom," he said wearily. He looked up at me with concern. "Promise me you won't cry? You know where I'll be."

"No, Georgie, I won't cry."

My son smiled, shook his head and lay back, eyes closed. Then he took a deep breath and was gone.

Mary Lou.

Rosemary.

George.

And so, again and again, people ask that question: "How

can you be happy after all that's happened?" I'll tell you how.

My children understood that life is a holy gift from our creator. They loved each day they were given, and their enjoyment and gratitude were like sunlight, warming and brightening our time together. In the face of early death, they embraced life. If they loved life as much as they did, honoring it, reaching out to soothe their stricken friends, using their days creatively, am I to love life any less?

No! I will not dishonor God—or my children—with gloom and self-pity. I embrace life as they embraced it and I shall rejoice and be glad in it! 