

Treasures of Unexpected Brightness

by Howard Martin

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Growing up, three of my siblings Olive, Alison, and Jeffi Martin were born with something missing from the cells of their bodies, an enzyme whose absence caused multiple, severe disabilities. The condition is now called MPS — Hurler’s Syndrome, but we did not know these names at the time (the 1950s). All we knew was that something deeply mysterious — and apparently inexplicable — was happening to them.

From a medical point of view, the shape of the mystery was quite similar for each of them. In about their third year of life, they began to have trouble breathing and would sometimes poke their tongues out between their teeth, as if clearing a space for air. Their stomachs began to swell (actually it was caused by enlargement of the liver and spleen), their hair grew thicker, and the shape of their faces changed. At a certain point, they stopped learning new words and began to forget some of the words they already knew. Over long months, they got weaker and weaker, unable to get out of bed, unable to feed themselves, unable to tell us where they were hurting. Their resources for fighting infection dwindled to zero and in the end they had no strength left to live. Olive died when she was 10. Alison died when she was 17. Jeffi died a few weeks after his 13th birthday.

I cannot honestly say that life was easy for us during those years. It sometimes seemed as if chaos had descended upon our house and we were constantly beset by small disasters: the keyboard of the baby grand piano tattooed with a screwdriver; an antique dresser redecorated with a bread-knife; hamburger meat from the refrigerator randomly applied to the dining room window; ink spilled in the aquarium and the fish belly up on the surface of the water; homework assignments spoiled, precious possessions lost, trips cancelled, visits to neighbors or friends cut short. My other siblings and I have many stories to tell--of awkward moments in public places, of messes to clean up, of sleepless nights, of emergency-room visits, and of baffled doctors coming and going. Every night, at our family prayers around the dinner table, we asked for a miracle--that Ollie, Allie and Jeffi would “get better.”

We never saw the miracle we had most dearly hoped to see. I guess that’s always the way it is with prayers. We did, however, have hints of another kind miracle, and bit by bit, we learned to see our siblings as gifts in our home just the way they were. They brought treasures of unexpected brightness to our family.

Among these treasures was the gift of song. My beautiful sister, Olive, was a singer. Long after she had forgotten many other things, she remembered the words and the music of songs she had

learned in the first five years of her life. Throughout the days she lived upon this earth, her voice remained pure and true, and the melodies she sang could fill our hearts with joy. She loved the old English folk song about London Bridge:

London Bridge is falling down,
Falling down, falling down.
London Bridge is falling down
My fair lady.

She would sing the refrain over and over again—my fair lady, a-lady, a-lady-- and we would all join in, answering her with the same words. The sweetness of the sound, the comforting familiarity of it, lingers even now in my memory.

Is there such a thing as a “gift” of serenity? If there is, then that’s the gift my third sister, Alison, brought into our lives. When we looked into her still, brown eyes, we saw no hint of anxiety or despair. We perceived, instead, a gentle reassuring light, that seemed to suggest that we were safe in the universe, and that there was no reason, ultimately, to be afraid. “Luh-hly,” she would say as she sipped a cup of tea, “Lovely.” She saw loveliness in a cup of tea and in the simple fact of her existence. By making short poems of her wonder, she revealed the essence of her life and made her own irreplaceable contribution to the world.

My little brother, Jeffi, gave us the treasure of laughter. His art was acting and he would put shows on for us at the drop of a hat. With our mother’s white gloves pulled up to his elbows, he’d give an impression of a traffic cop directing imaginary traffic along imaginary streets. He’d lace up our dad’s work boots, several sizes too big, and offer an improvised scene of a workman tending the family garden, chopping away at the lawn with a pair of long-handled edging shears. He’d dress himself as a motor scooter rider - crash helmet, riding gloves and all, and pretend he was speeding to far-away places, beeping the horn at slow-coaches and Sunday drivers on the way.

Jeffi saw himself as an entertainer and, in his own way, as a social critic. He thought dirty socks were a social problem, especially when they were left lying around the house. He would pick up a pair of well-used hose—never his own—and make a grand gesture of waving them in the air with one hand and holding his nose with the other. “PEEYEW” he would say, “PEEYEW.” He’d grin and dance and mimic and wrestle and play practical jokes, with never a hint of malice, and when the show was over, he’d give away strong warm hugs. He loved us all—even the stranger who came to the door— without condition. What more could we have asked?

In one of his books of Celtic wisdom, John O’Donohue writes: “The Divine Artist brought no child into the world without the light of Divine Beauty.” I was privileged to catch glimpses of that beauty in faces my own beloved siblings and I continue to see it in the lives of the hundreds of young people, with and without disabilities, who participate in the Jellybean Conspiracy.