

June 13, 1995

By Maureen Robins

Perhaps that night, my husband, Wayne, came home from work and made paella or baked cod, with small red potatoes, pygmy trees of steamed broccoli for us: our four-year-old daughter, Liz, and myself. After dinner, I did not clear the round wood kitchen table. I picked up my infant daughter J and set her in her stroller which was parked in our apartment's living room. I could only, for better or worse, focus on one thing, and that was not feeding our family, but nourishing J who in her eight months of life had not gained a pound since she was born.

J was in end-stage liver failure. Her body was a deep yellow, her skin stained by worn-out red blood cells, which are normally broken down but could not be filtered out of her body. The whites of her eyes, or the part of the eye that should be white, featured what looked like broken egg yolk—thick and permanent.

I pressed the button to start a slow drip of formula through her nasogastric tube, which, several weeks ago, during a hospital stay, I learned to insert. That was the condition of our discharge, and I didn't know whether it would be better to stay in the hospital which became our sanitary sanctuary and move J, who was seven months old, higher on the liver transplant list. Of course not. It was better to be home, in our comfort, and with Liz. Where Wayne could cook for us, use his anxiety for good and invest it in warm, tasty meals that could try to give us comfort.

The pump pulsed the special formula Dr. Levy ordered from its housing, an unobtrusive backpack draped from the stroller's handles and set in the tray beneath the stroller's seat. The drip released one pearl of nacreous liquid at a time which, with the help of its gentle force and a bit of gravity, sent dense calories into J's shrinking stomach tucked inside her swollen belly. She wouldn't throw this up, I thought. This will reach her gut as she rested, propped up in the stroller. The pump's beat was nearly soundless, a whispered tick, a subdued, kind, benevolent metronome easing the pace of our evening, quieting the noisy, fervent tick in our minds of the wait for The Call that a liver has become available. No, it was a tempered tap of flow, and milk, a string of gelatinous pears, helping us breathe as the darkness came.

I touched J's cheek, and we exchanged glances. As I looked at her, I felt for the beeper clipped to my hip pocket, the matchbook-sized device which should send a signal to me when to call the surgeon. I waited for any sign of life from the miniature electronic box. Last month, our transplant coordinator said, "always keep the beeper on you. You will have to call us immediately and leave home right away when it sounds." So far it had not sounded. Perhaps it didn't produce a sound, just a feeling, a vibration. I wondered if the thing even worked.

I left her side to clear the table as Wayne refreshed his glass with ice cubes and a

generous shot of vodka. He took a seat on the sofa to watch television. Liz followed and nuzzled next to him as they both sat on the sofa upholstered in forest green velvet.

I have taken to sleeping nights on that green velvet sofa. I feared something might happen to J or the pump would malfunction. I feared that if I was not there, right next to her, and she took her last breath, I would not hear it. I would miss the chance to fix the pump. I would miss the sound of her last breath. And worse, I would have missed an opportunity to revive her.

At 8 o'clock that night, the doorbell rang and the visiting nurse, a young, eager-to-please woman, dressed in a nursing outfit, arrived and brought street air with her. At this, a whirl of movement began: Wayne got up and sought refuge in our bedroom. Liz began to dance around the living room. The nurse is charged with checking J's vital signs, heartbeat, and blood pressure, that the feeding tube has been placed correctly by me through J's nostril, its end dangling in her stomach, and that the pump is set. J began to scream at the sight of the nurse, at the aqua shirt, at the stringent smell, at being touched by a stranger. J's eyes rapidly scanned the room for me. I hovered behind the stroller, ready to shatter. I couldn't stand the crying. I moved close to her so that I came into her view. Liz wrapped her arms around my hips. She said the nurse was there for her too and asked if the nurse would read to her. The nurse performed her duties and after half an hour agreed: she joined Liz on the couch and read Liz's favorite book, "When the Sun Rose," by Barbara Helen Berger. After the story, Liz agreed to get herself off to bed, and when I checked on her, she drifted off to sleep.

The phone rang. It was 9:15. Usually, Dr. Levy called between 8 and 10 every night to check in on me, on J, and how we were doing. I wasn't expecting to hear from him that night as he was on vacation.

It was Dr. Dunn, our surgeon.

"Come," he said.

"Did you say, come? Come now?"

Everything stopped.

"Yes," he said.

The moment arrived and it wasn't the moment I had been imagining every day for the past three months. I had imagined the beeper vibrating in my pocket, calling Dr. Dunn. But it is my moment. It was our moment. The moment we had been waiting for, full of promise that a transplant would take, and she would grow to be able to play in the grass, play tag with her sister, and feel an arc of air pass beneath her feet as I pushed her in a swing. But it was also the moment that promised an end rather than a beginning, that things could not work, and the surgery could go sideways. But I had hope and I fixed that hope firmly in my mind.

I placed the phone receiver back, got off the line with Dr. Dunn, and ran to tell Wayne to throw a bag together. We were driving from New York to Philadelphia.

I grabbed my Go bag which had sat in the corner of my bedroom for a month and dumped its contents on my bed. I began to repack. I opened drawers and grabbed clothes into my bag and J's things – a white sailor dress with a matching hat for when we leave the hospital,

a lavender flowered dress with a tiny jean jacket, pajamas, cloth dice that arrived this morning, sent by a friend who gave her son a piece of her liver when he could no longer wait for a cadaver organ, musical tapes, J's white tape recorder, a stuffed fabric yellow globe, Elmo, her favorite turquoise plaid blanket.

"Call your mother," Wayne said. We needed her to stay with Liz.

The night nurse found me to say she was leaving, it was 10 p.m. She wished me good luck. I shut the door behind her and when I do, I see myself outside myself shutting a door.

My mother arrives at 10:30.

"Traffic," she said.

At this time of night? I don't ask.

I brushed my cheek against hers, and we move past each other, she further into my apartment as I stepped out the door.

I take one daughter in the stroller and leave the other.

He will bring her later, I tell myself.

I was in parts. One part of me did the math: it would take us about two and a half hours from where we live to get to St. Chris. Dr. Dunn didn't say what time to be there. But I knew a donor organ becomes less viable as the minutes tick. I imagine the liver, bagged and purple, just flushed with preservative fluids, in a plastic bag set on a pile of shaved ice.

All packed and in the car, J buckled into her car seat as I sat next to her, Wayne accelerated to the on-ramp of the Long Island Expressway.

"We're on our way," I said. It was almost 10:45. It was dark. Clouds patched over whatever available light the night sky offered. There was a possibility of rain. Exit signs flew past like gates unmoored in a tornado. Traffic slowed and I read one of the signs.

"Wayne," I said, "We are going in the wrong direction."

We were driving east, toward the ocean, rather than toward Staten Island where we needed to veer off to New Jersey to arrive in Philadelphia. Is he as nervous as I am? He too must have been so afraid of what would be happening to our child or maybe he had had one drink too much. He snapped into focus.

It was nearly 11 when we began seeing directional signs for Staten Island—we were still nearly two hours away. J dozed off and I turn my head to view outside the car, outside the enclosed world we traveled in, where time had stopped but outside, time still flowed, the white ribbon of dividing lines, a moving morse code signaling distress, long and short dashes printed on a narrowing black asphalt path.

At the last exit of the New Jersey Turnpike, Wayne had to go to the bathroom. We turned off at a rest stop. He pulled up to a 24-hour restaurant and trotted to the restroom. I shut my eyes and opened them when I heard the latch of the car door opening. We still have at least thirty minutes to go. It is now close to midnight. Back on the road, within minutes, we see the green sign that said "Welcome to Pennsylvania." The hospital was in north Philadelphia and the directions were counterintuitive. There was a spot where we had to head north but we

took 95-S.

“Do you know where we are going?” I asked Wayne. He passed a sign to turn off that read “Philadelphia 4 miles.”

He says he does. We have done this drive before, just last month but we did it in the morning with the sun lighting the way, easing confusion and contradiction. As last time, we drove further south and took a later exit to the city. I had no choice but to trust him. This was the route. We were traveling on the unrecognizable road of our fate, a barely lit path into the foggy dark of the unknown.

We found the bridge and took the exit to I-95 S even though we knew we needed to head north. We began to see reflector signs “ER” and soon, a sign for East Front Street/Emergency Room appeared and we absorbed its reflected light.

We arrived at midnight when it is the custom for rabbis to wake to engage in prayer, meditation, and bible study. It is said during those hours of study they heal on a cosmic level. I tried to feel God’s presence beneath the streetlamps of the parking lot as I unlatched the car seat from its base cradling my dying child. We walked quickly and found ourselves standing before a double glass door that sensed our presence and slid open. We three entered a hallway. A nurse sat at a desk, her head illuminated by a desk lamp. We must have appeared like a couple who had hit bottom, who needed direction, absolution, two people who felt they must have sinned rather than celebrate good deeds to arrive here, at this place, and ignorant of the sin they committed, waited for redemption, for their baby to be saved.

“We have been waiting for you,” she said.

Maureen Picard Robins, who is an adjunct professor of English at SUNY Old Westbury and a student teacher supervisor at Queens College CUNY, was an artist in the schools in 1995 and a mother of two: a four-year-old daughter and her infant sister who at two weeks of life began to turn a shade of greenish yellow. Robins's work in progress is a memoir that attempts to understand the transformation of each member of the family in the effort to save the baby's life. Another essay, “[Dr. Altman's Letter](#),” from this work-in-progress has appeared in *Midway Journal*. She has published a poetry chapbook, “*The Transmigration of Souls*,” and children’s non-fiction and fiction picture books.