

# Ripped From the Headlights

Category: Stories

written by Maureen Picard Robins | December 19, 2008

**Maureen Picard Robins**

“Get a notebook,” he said.

Dr. Altman and I stood face to face on the pediatric surgical floor of Columbia-Presbyterian Babies & Children’s Hospital. It was the first week in December. A metal crib—it seemed more like a cage or prison—separated us. In this center space lay my yellow heart: my eight-week-old daughter, wounded by surgery, dulled by morphine, our whispers flying over her.

It had been nearly twenty-four hours since Dr. Altman opened the baby’s abdomen and held her tiny intestines in his hands, untwisting them like a fisherman untangling his line; nearly one day since he’d performed a Kasai procedure, fashioning a conduit so that bile could tremble down to her small intestine; one thousand four hundred and forty minutes since I’d been ripped from the headlights of the speeding car known as biliary atresia, a rare condition in which the duct from the liver to the small intestine is blocked or missing.

“There’s a lot to learn,” Dr. Altman said. “Write down all your questions. There is no way you will remember all this.”

There was only one question I wanted to ask, and I didn’t dare.

Besides that, there were so many other things I didn’t know. I didn’t know how long it would take for her jaundice to clear, or if it ever would. I didn’t know what to do if it didn’t clear. I didn’t know what cholangitis is. (It’s an infection in the bile duct, I learned; but I also didn’t know if I’d recognize an infection.) I didn’t know if her liver would regenerate from its “insult.” I didn’t know if I could trust my pediatrician anymore. Or myself.

Dr. Altman told me that about a third of babies who have Kasai procedures do well, period. About a third only partially clear their jaundice and eventually need a liver transplant. Another third don’t make it at all.

I got a notebook.

I wrote everything down.

Seven days later, the baby was well enough to leave the hospital, although we wouldn’t know the outcome of her Kasai for at least a month. In the meantime, Dr. Altman arranged for me to take her to see a pediatric gastroenterologist, Dr. Joseph Levy. I wrote down all my questions.

“Will Jackie live?” I wrote.

The next day, shivering in Dr. Levy’s office, I undressed the baby, who

promptly peed neon-green liquid into the cup of my hand. "It's all right," Dr. Levy said, meaning not to worry about the floor—but at that moment he knew that she would fall into one of the unlucky thirds, and he knew that I knew.

Dr. Levy asked to see my notebook questions. He answered them as best he could and wrote down instructions: how to trick a baby into eating bitter powdered medicine; how to feed her sweet potatoes on a nipple; how to dispense fat-soluble vitamins and a prophylactic antibiotic. He told me that he would phone me every night between 8:00 and 10:00 to see how we were doing, and that I should bring the baby back in two days. The next two weeks were critical, he said, and Jackie was fragile.

I got smarter. Through Dr. Levy and others, I met mothers of children who'd had biliary atresia and liver transplants. Until then, I had only read about liver transplants in newspaper headlines. Now I researched and cried my way through medical textbooks and journals while my husband, Wayne, took care of my older daughter, Elizabeth, and the household. The hue of Jackie's skin, urine and excretions told me that her first surgery was only a partial success, buying time. "The numbers are not going down," I wailed to Dr. Levy on the phone one night. "She's still yellow!"

A month post-Kasai, I took the baby back to Dr. Altman.

He counseled me to decide on a path and put all my trust in it. If something went wrong, I needed to be in a place where I could say, "I tried my best." No second guessing. No regrets. At that moment, I couldn't comprehend the picture he was painting. I couldn't even comprehend my own psyche: one minute I was humming lullabies, the next I was mentally boxing with God. But I agreed to take the baby to yet another specialist, Dr. Stephen Dunn in Philadelphia, to be evaluated for a liver transplant.

We drove to see Dr. Dunn the following week. He placed Jackie on the list, and we started our wait.

Dr. Levy continued to call me every night and to see Jackie weekly, but the struggle to keep her alive only intensified as we waited. She could not sit. She could not eat. And if she did, it came back at me. Her liver, sensing its own failure, grew to compensate. Her tiny belly swelled with liver and fluid. She had a herniated belly button.

Still we waited.

She itched all over. She could no longer hold her head up or gather the strength to roll over. I learned to insert a feeding tube, and Dr. Levy prescribed a powerful nutritional liquid to be pumped into her belly. One day in June, I said goodbye to Dr. Levy before he went on vacation.

That next evening, at the time when he usually called, the phone rang.

It was Dr. Dunn, calling to say, "Come, we have a liver for Jackie."

**About the author:**

Maureen Picard Robins is a poet and writer and an assistant principal in New York City. Her collection of poems *Transmigration of Souls* was published this year by [Finishing Line Press](#). She coauthored *The Good Teacher Mentor* (2003, [Teachers College Press](#)). Jackie entered high school last fall.

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