

PROLOGUE

GATHERING EVIDENCE

On August 10, 2009, a year and ten days after a hard-fought diagnosis of Lyme disease, I found myself face down on a cold metal table, lying in wait for a needle to enter my spine and wishing I'd never looked that image up on Google. It was stunning they would put *me* in charge of holding myself still for this procedure, considering my tendency toward spasms and twitches. I could have asked the doctor about it when he stopped in to say hello and introduce himself to Joe and me, but the thought of restraints kept me quiet.

“Hello, I’m doctor Ramesh and I’ll be inserting a needle the size of Apollo 13 into your spine today.”

No, he didn’t really say that ... probably. His accent was a little thick and I was a little distracted, but he did glance at my chart and say, “*What?* Are they looking for more *proof?*” He was incredulous! “They know you have Lyme disease. Aren't your symptoms telling them enough?” I held back a laugh. Not many doctors understood what Lyme patients endure because of the disagreements about diagnosis and treatment, but this guy seemed to know. Why is it, I wondered, was he the exception instead of the rule?

Not wanting to go down *that* rabbit hole, I grinned, shrugged, and deflected. “Well, I guess he has his reasons.”

Truth was, Dr. Johnson really *did* need more proof. He needed to justify the diagnosis of Neurological Lyme just in case intravenous antibiotics would be needed down the road. The infectious disease doctors in the hospital where he was director of neurology and co-director of neurosciences were known for fighting him on things like this, so while he promised to do whatever my Lyme specialist prescribed, Dr. Johnson was gathering evidence for my benefit.

Dr. Ramesh explained the spinal tap, told my husband and me it wouldn’t take long, and disappeared through the curtained wall in the outpatient center.

Joe kissed me for luck, and they wheeled me into the operating room, stopping in front of a long shiny stainless-steel table. My stomach and throat tightened in sync. Dr. Ramesh smiled and gave assurances they would do whatever they could to keep me comfortable. I asked him about the computer monitor over the table and he explained how the table would transmit pictures of my spine to the monitor to guide him during the procedure. I still can’t remember

how I got onto it, but in a matter of seconds I was belly down on the rock-hard surface with nothing to cover me but a flimsy hospital gown, open in the back. Joe was just outside the door, one thin wall away, and a nurse stood by my head, stroking my hair, talking softly.

“You’ll have to hold very still,” she said kindly.

I nodded with a sense of forced compliance, biting my lower lip and trying not to cry. *This is really happening*, I thought.

“You’re doing great,” she said. “We’ll be done soon and then you can go home and have a nice rest.” It’s funny how a total stranger can step into your mother’s shoes sometimes.

With my eyes closed, I tried some cleansing breaths but abandoned that idea when I noticed my back moved with every inhale. *What if I just don’t breathe? That’s probably better.*

Something cold and wet touched my spine and I flinched. The nurse leaned over so I could see her face and explained this was to sanitize the area before the doctor injected local anesthetic.

Dr. Ramesh gave me a heads up on the first injection. “This is going to sting a little.”

The nurse held my hand and I held my breath, doing my best to not crush her fingers as the anesthetic went in. “You’re doing great,” she repeated. A tear rolled down the side of my face at the sheer powerlessness of my situation.

Up next is the big one. Don’t move. Don’t breathe. Don’t fight it. A little voice inside screamed out at the unfairness of being asked to just lie there, waiting to be hurt. But even in my despair I knew, as dear Bella once told me, the only eventual way out is through.

“You might feel a little pressure,” the doctor said.

There *was* pressure. It was unexpectedly followed by searing pain shooting through both of my legs. I possibly recall hollering “get it out get it out get it out” as Apollo 13 was removed, and Dr. Ramesh’s voice announcing he would have to start over. It’s hard to be sure what was dreaming and what was real. According to my journal, they had to sedate me for a second stab at it.

The next thing I remember, my eyes were fluttering open into Joe’s.

“Hello, Bunny.” He kissed me gently. “How was your nap?”