

Watching Their Dance

a memoir

Three Sisters, a Genetic Disease and Marrying into a Family
At Risk for the Worst Disease on the Planet

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INTRODUCTION

Forty years ago, a strong, cold wind blew into my life and upended everything.

I was in love with a man I planned to marry. He was extremely close to his three sisters, and I loved them as deeply as if they were my own family. I looked forward to one day having a beautiful wedding, bearing children, enjoying many good times with these women, growing old with this man.

Then we learned that all four were at risk for Huntington's, a horrific neurological disease.

Woody Guthrie, the great songwriter and singer, is still the most famous person to have suffered from this fatal genetic disorder, which causes the progressive breakdown of nerve cells in the brain—leading, eventually but inexorably, to the destruction of one's physical and mental abilities. It's been likened to having Parkinson's, Alzheimer's, and ALS at the same time. Every child with a parent who carries this mutated gene has a fifty percent chance of inheriting it.

The disease usually manifests when one is between thirty and forty-five years old. When Guthrie died, in 1967, there was no test to determine who carries the mutated gene, no treatment, and no cure. There's a blood test now, but still no treatment. And still no cure.

Because only seven to ten percent of those who might have inherited the gene decide to be tested, it's not known how many people are at risk worldwide. The highest frequencies of HD are found in Europe, Australia, and the United States (with one hundred cases per million people). The lowest documented frequencies of HD are in Africa, China, Japan, Finland (with six cases per million people), and Hong Kong (with 3.7 cases per million people).

But numbers mean nothing when the risk of developing this disease comes into your life, as it did mine. John and his sisters had not had a happy or nurturing childhood, and I admired them from the day we met for their ability to be positive, loyal, fun-loving, forgiving, and kind. What I learned from them could never be found in a book, a classroom, a religious setting, or a therapist's office. Forty years ago, I took the biggest gamble of my life by keeping these people in mine, and it has made me the person I am today.

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Some lives seem to move smoothly along a natural continuum, with one event or decision seeming to slide into the next. Such people seem to have faced no dramatic forks in the road, had few life-altering choices to make. Other lives, at least in hindsight, travel in a particular direction at one particular life-changing moment. That's what happened to me, when, at age twenty-two, I suddenly had to confront the most complicated decision of my life.

I met John Anthony Marin in 1976, when we were attending junior college in Contra Costa County, across San Francisco Bay on the far side of the Berkeley hills. I was twenty and he was one year older, with light brown hair and kind hazel eyes, tall, handsome, and athletic; I fell for him immediately. We felt so close so quickly, it wasn't long before we were a couple.

I quickly learned that being with John meant having his three older sisters in my life as well. The four had had a difficult upbringing and were exceptionally close. Their mother had been placed in a psychiatric hospital when John was just a baby. Their father, Big John Marin, would never tell them why their mother was gone and when she might come back. Of course, his life was difficult, too: In addition to having four children under age six and working full-time, he helped his elderly immigrant parents manage a five-acre ranch next to his home. Even so, he didn't seem to take much interest in his children, never showing them affection or encouragement, only criticism and negativity. He treated his oldest daughter, Lora, as a housekeeper, and the others just stayed out of his way.

When I met them, Lora was twenty-eight, a blond, striking woman with a creamy complexion, twinkling eyes, and a welcoming smile. Her generosity and bubbly personality drew people to her; I always felt a light radiated from Lora. By day, she was a secretary at an accounting firm in Sacramento; by night, a highly creative chef. I loved visiting her and her husband, Dave, a jokester and life-of-the-party kind of guy. He and Lora had become a couple when she was fourteen, and Dave had embraced John, then eight, like a big brother.

Marcia was twenty-six. She was shy but sophisticated, glowing with gentility—the first woman I knew who looked chic in jeans, maybe because she had them dry-cleaned. Her light brown curly hair and makeup were always impeccable. Neither sister had a college degree; after Marcia graduated from high school, she'd gone to work in San Francisco in the typing pool at Pacific Bell. But she was smart and ambitious, and ten years later, her title was Marketing

Representative. She lived in an apartment in Walnut Creek, about fifteen miles east of Oakland. She'd been with Glenn, a local realtor, for several years.

By the time I began dating John, Cindy, two years older and his childhood buddy, was working as a dental assistant in Surrey, British Columbia, just above the Canadian border. She visited during the holidays, so I'd been with her a few times. John called her a "free spirit" and the positive force in their family. Like John, she had a wide smile and hazel eyes, and there was no denying their kinship.

Whenever I was around the sisters, I noticed how they doted on their little brother, who, at six-foot-three, towered over them. It had become clear to me how much they supported, protected, and defended one another, no matter what. We spent lots of time with Lora and Dave, Marcia and Glenn, playing softball, having barbecues and parties, camping, just hanging out.

At times, I envied the Marin siblings' relationship. Even though they'd had such a challenging childhood, John and his sisters were all positive, fun-loving, giving individuals, so different from my Catholic-ritual-driven, take-no-chances family. I'd grown up in a home where the first reaction to just about anything was negative, and I'd been taught never to draw outside the lines. Independence and self-esteem were never encouraged; instead, my parents used guilt, a good Catholic method of control, to motivate my sisters and me. How could I not feel guilty when I felt closer to Lora and Marcia than I did to my own sisters?

By 1978, my relationship with John had become a long-distance one—four hundred and eleven miles, to be exact—since he was at California State Polytechnic University (Cal Poly) in Pomona, and I was attending the California State University in Sacramento. John would drive the eight hours to see his sisters and me as often as possible, and whenever he was home, we stayed with Lora and Dave. We had so much fun during those visits, I never minded sharing him.

Our lives changed dramatically one Saturday afternoon in early November. Though Thanksgiving was just a few weeks away, John's sisters had asked him to come home that weekend and to bring me with him to Lora and Dave's house that afternoon.

Cindy was there, too, having flown in from Canada the previous week. I wondered why she, too, was there before Thanksgiving. John's sisters and Dave greeted us at the door with their usual smiles and hugs. John and I sat on the comfortable white couch as his sisters finished preparations for dinner and Dave took a phone call. I looked at Bubba and Cedrick, their Keeshond dogs, lying on the brown shag carpet in the sun; at the custom-made macramé hanging I'd always admired, above the brick fireplace; at the framed photographs of Dave and Lora, the Marin siblings, Lora holding Bubba with a huge smile, on the sand-colored walls. The fire roared in the hearth as soft

music played on the stereo. This cozy room, always such a safe haven, now felt strangely cold and unfamiliar.

My apprehension grew as the sisters' whispers floated into the living room. Turning to John, I murmured, "Do you have any idea what they want to talk to us about?"

He shrugged. "It's something to do with our mom's side of the family, but other than that, I'm as clueless as you."

Just then, the three sisters entered the room. I felt the hair on the back of my neck stand up. Dave leaned against the doorframe as Marcia took a seat across the room, crossed her legs, and wrapped her hands around her knees, smiling vaguely, like a Cheshire cat, I thought. Lora sat next to John and began patting his thigh and nodding as if to say, "Everything's going to be all right." Cindy pulled up a footstool and sat down in front of us.

"The three of us visited Aunt Evelyn last week," she began. "It's been years since we'd seen her, and we decided it was time to reconnect." She looked at me. "She's our mother's younger sister; she lives about an hour south of Sacramento, in Galt. We learned from her that we have a genetic disease in our family, called Huntington's disease. Our mother, Phyllis, and three of her siblings had it." She paused a moment to let the words sink in. "We rarely saw our mother's siblings after she died, so we were unaware that they had suffered from it. It's an inherited disease that causes the progressive breakdown of nerve cells in the brain. It affects muscle coordination and leads to behavioral symptoms and, um, mental and physical decline."

"Aunt Evelyn was shocked that we didn't know about the disease in the family," Lora added.

"Since Dave and I don't have any kids and Marcia and Cindy are single, she assumed we'd made these choices because of Huntington's."

My hands squeezed John's like a vise, and I moved so close, I was almost sitting on his lap.

Otherwise, no one moved; it felt as if an icy despair had frozen everyone in the room. My eyes darted from sister to sister. The word *what* formed on my lips, but I couldn't make a sound.

The only thing I knew about Huntington's was that the great American singer and songwriter Woody Guthrie had died of this terrible wasting disease, and that his last years were even worse than they had to be. Slowly losing control of both muscles and cognition, he became increasingly erratic. At first, he was deemed an alcoholic and then diagnosed schizophrenic. Like John's mother, he lived in psychiatric hospitals for years until he died.

Cindy, always the fearless one when it came to dealing with their father, said, "After the visit, I called Dad and asked him if what Aunt Evelyn had told us was true. I pressed him for answers, but you know Dad. He got angry and never admitted that Mom had had Huntington's."

Coming out of her trance, Marcia said, “The good news is now we know what was wrong with Mom. But the bad news is we each have a fifty-fifty chance of inheriting this disease. And there is no test or cure.”

Cindy went to the French doors and stared out at the piles of crimson leaves in the yard. Then she turned and faced us. “I’m tired of not knowing why things happened in our lives. Dad kept us in the dark, not just about Mom but about everything. It wasn’t fair, because we deserve to know, especially about this.”

Lora said, “We asked him for Mom’s death certificate, and he refused to show it to us. So Marcia went to the Contra Costa County recorder’s office and got a copy, and sure enough, it said, ‘Cause of death, strangulation,’ with Huntington’s disease as the underlying cause, because she’d had to be tied down in her bed.”

The room grew silent again. Lora continued to pat John’s thigh while watching me. “We’re sorry to drop this on the two of you, but since you guys are talking about marriage, it’s only fair you know about the family, Therese.”

I blinked my eyes rapidly, trying to clear my head, and looked at John. He just smiled and squeezed my hand tighter. After a few moments, Lora said briskly. “Okay, who wants a drink?” “I do,” we all responded simultaneously.

As she and her sisters walked into the kitchen, I shouted, “Double shot of bourbon for me, please!” John sauntered across the room and began talking with Dave; Dave slapped John on the back, and they immediately started to laugh.

I leaned back on the couch and took a deep breath as I felt this compelling information slowly registering in my consciousness, alerting my senses to danger. A struggle began between my brain and body: As anxiety and doubt crept into my mind, a primal instinct screamed, *Run*, but my heart said, *Stay*. I felt as if I were being pulled one way and then another, back and forth, back and forth.

My body jolted to a stop when John sat down. “Here’s your drink, Therese. Are you all right? Did I scare you? You jumped when I said your name.”

“No, no, I’m fine, just...just a little chilly. Can you get my sweater, please?”

John returned with my sweater and wrapped it around me. “Are you warm enough now?” I nodded and took a gulp of my drink. When Dave turned on a football game, John’s head snapped toward the TV, and he moved to the edge of the couch.

Stirring the ice with my finger, I stared at the russet liquid as my racing heart slowed down. I felt as if I had just watched a scene from a bad play and the curtain had come down with a thud.

Needless to say, I was glad it was over and the actors back to their usual selves, but my anguish

remained. I had no idea why the sisters had sought this information now. So many questions were popping up in my mind, and unfortunately, they would remain unanswered, because the final act of this play was unscripted, the starring actors unknown. Happy or tragic, the ending would play out only over time.

I looked at John and Dave, cheering for their team, and watched the sisters laughing in the kitchen. Were they trying to put on a good face for me? No, they'd chosen to ignore something they could do nothing about, at least for now. So I tried to change my frame of mind, too, and went into the kitchen. "Can I help?"

At dinner, Lora kept serving us her delicious lasagna, arugula salad with glazed walnuts and mandarin oranges, the world's best garlic bread; Dave never stopped pouring wine and telling funny stories, and we got through the meal. By the time we were devouring Lora's homemade apple pie with vanilla ice cream and Irish coffee, life seemed almost normal. For these four siblings, the new reality meant living at risk for a terrible disease, for how long, no one could predict. All they could do was push the thought aside for a while.

The next morning, John and I said goodbye to his family and went back to my apartment. It was about a mile from campus, your usual two-bedroom student digs, with posters of Rod Stewart, Kiss, and Fleetwood Mac on the walls, a little balcony off the living room where we stored our bikes. We had it to ourselves, since my roommate, Mary, had gone home to Martinez for the weekend. John and his sisters had also grown up in Martinez, an oil town about fifteen miles west of Walnut Creek, on the south side of the Carquinez Strait. Martinez had been home to a Shell Oil refinery since 1915, and its tanks, buildings, smokestacks, and hundreds of miles of pipes covered a thousand acres of land. Every year, oil tankers docked in the Martinez marina unloaded thousands of gallons of crude oil and shipped out thousands of gallons of refined gasoline and other petroleum products. When you drove past the town on Interstate 80, the smell of oil permeated the air for miles. John and Mary had gone to high school together; in fact, she was the one who had introduced us, at a party in Martinez when we were all attending junior college. As we studied, I wondered how John felt about the shocking family secret that could change his life, but I didn't know how to bring up the subject. There really wasn't enough time to talk anyway, and I wanted to enjoy the time we had left that weekend.

At one o'clock, John looked at his watch and closed his book. He had to get on the road, and in a few hours I had to start working in the men's department at Weinstock's, then "Sacramento's finest department store."

John gathered up his stuff, then stopped and leaned back in his chair. “I know we haven’t talked about yesterday, and you must have a million questions. How about we talk about it over Christmas break? It’ll give me time to discuss it with my sisters and get some of my questions answered. You probably have the same ones.”

I reached across the table and took his hand. “That sounds good. And I’ll try to find more information about the disease.” In the parking lot, we stood next to his car, unwilling to say goodbye. As we hugged one another, I leaned my head on his chest. “Be careful on the freeway,” I said. “I’ll call you Friday night.”

John drove out of the parking lot waving and honking his horn. As soon as he disappeared, the realization that my life would never be the same hit me. I stood there a few minutes more, tears rolling down my face.