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The Year of Living Nervously

I'm half asleep when my parents walk into the room, but they do not turn on the light. My parents hardly ever come into my room, alone or together. They stand there for a moment, silhouetted in the doorway. They both sit down on my bed, which is very uncomfortable for all three of us because I'm sleeping on a Castro convertible, one of those narrow pullout sofa-type beds popularized in the '50s and '60s by a television commercial featuring a pixie-like eight-year-old girl in a nightgown who effortlessly flings open the contraption, a feat that caused permanent disc and hernia damage to scores of burly grown men who gallantly attempted the same act at home.

My mind races. *This is it*, I say to myself, *my parents are getting a divorce*, and I try to think who I want to live with. My father is lenient and easy-going but my mother is a terrific cook. My father never makes me wear a sweater or gloves or, God forbid, the dreaded rubbers (a.k.a. galoshes) when it rains, but my mother let it slip that our house and two cars are registered in her name, a shrewd business decision made by my dad in case of lawsuits and the like but a decision that, nonetheless, gives my mother the edge.

I'm trying to make a choice and let down one of my parents easily when my mother's voice cuts through with, *Your brother has leukemia*. I know right away they're talking about my almost two-year-old brother because of his low-grade fever that never seems to go away. The fever that, it turns out, a host of doctors initially misdiagnosed; instead of investigating they placated my parents with a wave and a prescription.

I know I'm supposed to react, to say something, and I think of those shows I watch on TV like *Marcus Welby M.D.* where Doctor Welby tells a patient they have some terrible disease and they scream *Nooo! Nooo!* and carry on, but all I can think about is the past week's episode where Doctor Welby told Cloris Leachman that her teenage daughter had a venereal disease and didn't know who gave it to her and there was this dramatic music and a close-up of Cloris's face and she screamed *Nooo! Nooo!* But this isn't the same kind of thing at all.

Do you have any questions? my parents ask me, and I don't, which isn't true, but I don't want to talk, not right then. *You can cry if you want to*, says my mother, but that's something I really don't feel like doing, and my mother feels my cheek in the dark to double-check. And then they leave me alone on my Castro convertible.

I'm in gym class the next day, three weeks into ninth grade, and we're playing softball and I'm in my usual position which is far out in right field. So far out in fact, that there isn't any possibility that I will ever come in contact with the ball.

I think about what my parents have told me the night before and I start to get into this metaphysical thing in my head about life and how short it is and that nothing really matters much and that everything I've been worrying about like being a geek and not having any friends means squat compared to my brother having leukemia, so I lie down on the cement because hey, I'm so far out in right field, who's going to care? I close my eyes, careful not to stare directly into the sun so I won't go blind, when the shadow of Mr. Ratner appears above me, like God has decided to show himself in the form of an angry gym teacher.

Just what do you think you're doing? he asks, his face all flushed.

Getting a tan, I answer, and the minute I say it, the moment those words fly out of my mouth, I know I've made a big mistake.

Get up! he commands, and I stand, and he leans into me. *Are you retarded?* he asks.

No, I'm not retarded, I say.

Don't you have any school pride? he asks. *Don't you have any school spirit? Don't you care about your team? Don't you know that they're depending on you?*

Depending on me? I think. Oh, so that's why my team put me so far out in right field I'm practically off school grounds, which is interesting because we're always lectured by the principal that we should never, ever step off school grounds and here I am, so far off school grounds I'm practically in another school zone.

Would you rather spend gym class in the library, is that what you'd like? Have me write you a pass to sit in the library? Mr. Ratner snarls.

Now this is clearly a trick question because of course I'd rather spend gym class in the library, but I know that I can't tell Mr. Ratner that, so I look at him and think what an idiot he is and how he will spend countless gym class hours yelling about team spirit. A few years later Mr. Ratner will develop a debilitating genetic disease and die before his fortieth birthday, but, of course, I do not know this at the time, so I bow my head like I'm all sorry and stuff and mumble, *No*.

Let's play ball! bellows Mr. Ratner, satisfied that I have come to my senses.

My freshman year begins and so do my brother's cancer treatments at one of the largest hospitals in the city. His prognosis is not good, but I do not know how bad it really is at the time. My brother's pediatrician had referred my parents to a specialist for what they assumed was another in a series of frustrating appointments to solve the mystery of his stubborn fever. They were ushered into a large conference room with several doctors, all in white coats, sitting around a rectangle conference table. There they were given the news.

We have a program for children with this disease.

We put them in remission, which lasts about a year.

We give them radiation and chemotherapy.

Your son will be dead in two years.

One of the doctors attempts to comfort my mother.

You're still young enough to have another child, he says.

My mother is forty-four.

What good is this big house? my father cries behind closed doors to my mother about our new four-bedroom colonial on the south shore of Long Island. The one we moved to from our four-room subsidized housing complex in Brooklyn after we left our one-bedroom walk-up five blocks from the mouth of the Williamsburg Bridge. *What good is all this money when my son is dying?*

My mother wraps her arms around him, *The strong one who kept the family together* my father recalls.

My little brother is tied down to a metal table and a beam of radiation is applied to his spine. No one is allowed in the room, so he cries. He is a few months short of his second birthday. My mother and father sit outside the room with a microphone and sing to him. The minute they stop, he starts screaming, so they keep singing. Over and over they sing, one song after another.

My father seeks answers and subscribes to magazines, journals, newspapers, whatever he can get his hands on that might give him more information about acute lymphatic leukemia. Information about a cure.

My mother, who has never driven a car, begins driving lessons. We stay out of her way. She backs out of our garage without opening the garage door. She annihilates all of our garbage cans. She informs us that she will not drive at night. She will not drive on the expressway. She will not drive during rush hour. She will not drive in any town but the one we live in. She will not parallel park. She will not allow us to criticize her driving.

I need to be independent, she pleads, so we clear the driveway and let her.

I am unofficially appointed Guardian of Germs, responsible for shielding my brother from the coughs and sneezes that can easily compromise his tenuous immune system, a challenging task which requires *Mission: Impossible*-like planning, precision and synchronization.

Your brother will be treated like any other child, my parents demand, which means that with the exception of our immediate family and a few select relatives, no one knows about his condition. Which also means that although my parents want the kids from our street to want to play with my brother, they do not want them to actually *play* with my brother. They can get close, but not *too* close.

During my little brother's second birthday party, we devise an elaborate plan of deception with me politely maneuvering my brother from room to room, much like the superfecta at Aqueduct Raceway.

Aunt Stella sneezes—and we're off, from the living room to the den. But

Uncle Sid corners us and he coughs, loud, raspy and phlegmy, so we take a quick U-turn to the dining room. Watch out! Grandma Annie is there, and she's sniffing, dabbing her nose with shredded Kleenex, so we head down to the basement where Cousin Richie blocks our way. Is that an eye infection? Conjunctivitis? We flee to the second floor and to the safety of any one of four bedrooms. At the end of the afternoon I am exhausted, yet relieved: mission accomplished and immune system saved. For now.

We plan a family vacation during winter recess, a trip to Miami Beach. My aunt, a travel agent with a lousy track record, makes the arrangements. *It's a beautiful luxurious hotel right on the beach* she gushes about our accommodations. The "hotel" is actually a motel, small, noisy and two blocks from the Atlantic. Worse yet, the heating/air-conditioning is controlled from the front desk which leaves us in a perpetual state of either heatstroke or frostbite. By the next morning my brother's temperature is one hundred and five. Overnight my brother's protective armor, the one we all brilliantly executed for months, is undone by a cheesy motel with a crappy ventilation system. Guardian of Germs, my ass!

My father explains our plight to a supervisor at Delta Airlines and they arrange for us to fly home on a chartered jet, just the four of us. I know this sounds unbelievable and all, I mean, asking for a blanket or pillow on an airplane today involves pleading and bribery and here we are with our own *airplane*, but whatever my father says works a miracle and the captain radios for an ambulance to stand by on the tarmac and we are taken directly to the hospital where my brother is admitted. I feel like I'm in a scene from *Airport* and Dean Martin has just radioed ahead for George Kennedy to clear the snow drifts from runway five in anticipation of the crippled jet's arrival.

My brother's crib looks like a miniature steel cage at the zoo. My mother leaves the room for a moment and returns to find a group of interns encircling my brother—who is crying hysterically—somerly studying him like a science project, writing and notating.

Get out! Get out! my mother shrieks and physically pushes them away with such force that they flee.

The head of the oncology department investigates the commotion.

You make sure that never happens again, my mother warns him and for the rest of my brother's stay at the hospital the inquiring interns stay clear of his room.

My brother returns home and he is playful. But some nights I awaken to find my father bathing him in a cool bath to lower his fever. And on those nights, my parents sleep with an open line to the hospital until morning.

My father continues his research and one day he reads an article about clinical trials of a new drug called methotextrate, a potentially promising treatment for kids like my brother, but with unknown side effects. He is elated.

My mother is terrified.

I will not send my son to be a guinea pig for a new drug! she says.

My father waits; lets her think about it some more.

After twenty years of marriage, I learned to drop the subject when your mother was so adamant, he later told me.

But two days later he brings it up again.

He'll die if we don't try it, he says.

And my mother knows that he is right.

The summer before my sophomore year in high school, my brother begins the new methotrexate experimental drug treatment with another little boy named Damian who is a few years older. Week after week they offer their fingers together for their blood counts, like a game on *Romper Room*. Damian's mother and my mother warily sit and chat.

There are other children in the hospital waiting room that summer. I notice that as the weeks pass the waiting room seems emptier. There are less kids and less moms. I mention this to my mother, but she stops me in mid-sentence; her face says, *I don't want to hear that*. I realize that the missing kids and their moms are never coming back. Each week we return, and someone is missing. This becomes my secret guessing game. Who will be next? Like the mystery of *Ten Little Indians*. Damian remains, and so does my brother. Every week they run and hold up their little fingers for a prick of blood. And they grow stronger. And soon they will be the only ones left in that waiting room.

At home, my parents mix my little brother's medicine in his food, but he tastes it and spits it out. They put it in everything, apple sauce, cream of wheat, ice cream, but he spits. They hold him down on the kitchen table to make him swallow and try to stop the spit from hitting them in the face. I watch my parents as they struggle for hours to get this one little pill down in his stomach because they know that there are other, more unpleasant ways to get that pill to stay down, and by this time my little brother has been poked and prodded with too many needles. I am amazed that they have the stamina for this, that they won't give up.

My older brother is home from college. He has long hair, wears bell bottoms, shirts with fringes, and multi-colored belts that tie together in the front. The summer before, he told my parents he was going to a small concert with some friends and the concert turned out to be Woodstock and my parents almost had two heart attacks watching it on the news, so now they listen very carefully to what he tells them.

"Mr. Woodstock," as I sometimes refer to him behind his back, spends days shuttling back and forth with me to the hospital for my little brother's frequent blood tests. We find an empty room and watch television on one of those dopey looking devices suspended from the ceiling. A woman comes

into the room, a social worker. She wants to talk to us about our feelings. Mr. Woodstock and I are polite, but we don't want to talk about our feelings; we want to watch *Hollywood Squares*. But the social worker persists.

What do you feel? she asks, repeatedly.

We feel that we would like you to get the hell out of the room so we can hear Paul Lynde give the answer to the Secret Square question, I think to myself.

I just want to know how you feel, she asks again, for what seems like the zillionth time.

We ignore her because we're trying to hear how Wally Cox will answer his question, so the social worker furiously scribbles on her clipboard. The more we ignore her, the more she scribbles. Finally, she stands, lets out a deep sigh, and whispers, *I'll leave you two gentlemen alone now.*

That's fine with us, because the contestant from Spokane has just chosen Charley Weaver for the block.

The social worker tracks down my mother in the waiting room. This is a huge mistake. My mother is pacing, awaiting the results of my little brother's latest blood test. She does not want to talk about feelings, hers or anyone else's. She tries to be polite, to walk away, not to make a scene, but the social worker persists.

I know how you feel, she tells my mother. Another big mistake.

Oh, you do, do you? says my mother and walks toward the social worker in a kind-of-threatening manner.

Is your child sick? she asks the social worker. *Does your child have leukemia? Did your child have radiation?* and the social worker shakes her head, no, and backs away with her clipboard. My mother takes a deep breath, apologizes, and says, *I'm sorry, I can't talk to you right now, please leave.* And my brother and I silently chant, *Go, mom!*

But the social worker has the last word.

Years later, I will read her clipboard and her scribbles: *brothers, uncommunicative; mother, hostile and uncooperative.*

My older brother takes me to my first concert that summer to see the folk-rock singer Melanie outdoors in Central Park.

You might see some unusual things, so don't freak out, he tells me in the car as we drive through the Midtown Tunnel.

And whatever you do, he instructs sternly, *don't tell mom and dad, or I won't take you anywhere again. They've got enough to worry about.*

I have no idea what I might see and I don't know what he means by freaking out, but it seems like something I shouldn't do, so I say, *Okay, I won't freak out, and I won't tell mom and dad. And, yeah, they've got enough to worry about.*

I arrive in Central Park that night expecting to see hordes of crazy people running around and screaming, but everyone around us is very well-behaved, even though they are all smoking pot. My brother looks over at me, but I

pretend not to notice because if I notice he'll think I'm freaking out, something I have promised not to do. When Melanie sings "Candles in the Rain," somebody lights a flame and holds it in the air. My brother gives me matches to light so I hold my flame until it burns my fingers, and my brother rolls his eyes and hands me his Bic lighter, and we all sing "Lay Down, Lay Down" with Melanie and rock back and forth, and suddenly I feel a little less uncool.

In between hospital visits, my older brother and I go to the movies a lot that summer, and it seems that almost everything we see stars this new actor named Elliott Gould, and for the first time I understand what my brother means when he says, *Don't tell mom and dad*, because all of these movies are rated R, which means I can't see them unless I am accompanied by a parent or adult guardian, not my brother. I really don't think that with everything my parents have to worry about, they'll care that I'm seeing a bunch of raunchy movies, but I don't tell that to my brother.

My older brother drives me into the city to have my hair chemically straightened because straight hair is cool and curly hair isn't, unless you're black, which we're not, and the white chemicals burn my scalp and I end up with hair like straw. On the drive home our car stalls on the on-ramp to the Belt Parkway and a man drives up next to our car and my brother thinks he's going to help, but the man leans over and asks us if we want to get our heads blown off and we freeze.

Would you like me to come over there and blow your brains out? he asks again. Slowly, slowly, my brother locks the doors and raises the window, and the man drives away. We don't move until the tow truck arrives and I know, without my brother telling me, that this is *definitely* something *not* to tell my parents.

Ten days later my brother leaves for college. I will miss him and the R-rated movies, but I am happy that we were almost murdered together in the middle of Brooklyn with our newly chemically straightened hair. We *bonded*, as people say in current popular vernacular. And that makes me smile. I am happy.

Until Damian, my little brother's comrade in the pediatric ward, dies at the end of summer.

We find out about it while driving to the Jersey shore before the start of the new school term. My mother sorts through the mail and I see her open one of those Hallmark greeting cards with lots of flowers on it, and she starts to read and then closes the card, moans a bit, and throws her head back.

I have a migraine, she says softly, and doesn't talk for the rest of the three-hour drive.

The card is from Damian's mother, my father tells me later that day while my mother is resting. I read the card from Damian's mother, written in beautiful penmanship, about Damian's last days, about how he didn't suffer

and how he is in a better place, and I know that my parents don't buy the stuff about him being in a better place, that they don't believe in that stuff, that the only place to be is here with all of us.

We drive home, me in the back seat of our family's 1971 El Dorado with my little brother beside me. I don't fully grasp the immediate impact of Damian's death on my parents. I don't *get* it, what they must be thinking, the still-too-fresh memories of a group of children in a hospital waiting room who slowly faded from life.

The realization that their son is now the Tenth Little Indian.

The survivor.

He is the last one left alive.

The first and longest-surviving child from one of the largest hospitals in the metropolitan area with acute lymphatic leukemia to embark on a risky and unproved treatment and live to adulthood.

Where he remains and thrives to this very day, more than thirty years later.

Shortly before my mother's death in 2005, I asked her about that time in our lives and how she and my father coped in an era before "Oprah" and "Phil," before support groups and chat rooms and self-help books on Amazon.com. What was *it*, that *thing*, that *formula* that kept them going, especially during that torturous first year?

We did what we had to do, she replied as if *doing* was the most natural thing in the world.

How? I asked. *Didn't you get depressed?*

My mother appeared puzzled by this suggestion. *Depressed? Who had time? Your father had a business and I had a house to run and three children to raise. Every morning we got up, got dressed and put one foot in front of the other.*

But, still, I wondered. How do you get through something like this? How do you manage when you're told that your child may only have two years to live? When you've just moved to a new home and started a new business. When you have elderly parents of your own who need looking after. How do you do it?

And as if reading my mind at that very moment, my mother told me.

One day at a time.

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