

1

Twenty years ago my father shot himself. The police who investigated the incident made the logical assumption that he was murdered since there were two bullet wounds in his head and no one can shoot himself twice in the head if he is committing suicide. What they couldn't have understood at the time was that my father had an accomplice who put the second bullet in his head to make it appear as if he had been murdered. As I was to learn later, the idea of making the suicide appear as a murder was to frame Mitzi's father, this lousy sonofabitch, who had been threatening my father and our family, and against whom the police were unable to bring charges. If that seems like a rather drastic way of getting someone off your back, you have to understand that my father had Huntington's Disease and had already decided to kill himself anyway.

That was in 1982. I was seventeen years old at the time, a senior at Scotch Plains High School in New Jersey, hoping to go to Juilliard when I graduated. I went into what the professionals label as a "reactive" depression and gave up playing my violin. The beauty of a Mozart violin sonata had lost its appeal and *like father like son* I went on a drinking and drug rampage, which, as you'd expect, deepened my depression during those intermittent moments when I was sober, to be relieved only by the high that addiction offers. Thus, there was the familiar cycle of depression and drugs until you hit rock bottom, at which point you either died or recovered.

I think, without a doubt, my recovery process was exacerbated after being in a New Year's Eve car accident. I had drifted over onto the other side of the road and was hit head on by another car driven by someone equally as

stoned as I was. I spent six weeks in the hospital with a partially crushed sternum and multiple arm and leg fractures. Today, I still have a set of screws holding together a shattered clavicle, which never fails to remind me of how close I came to dying a pretty stupid death. You might add that lying in a hospital bed, your limbs weighted in plaster casts and living on morphine, along with a catheter stuck up your dick, beats AA and NA as a place to become reflective on how you've managed to fuck up your life.

My mother didn't tell me about my father's genetic flaw until two years later after we had moved out to San Francisco, California. I was in my sophomore year at the University of California at Berkeley and had pretty much started to become a human being again following my recovery from the automobile accident. My mother later confessed to me that she worried that telling me that I was at risk of one day becoming incurably demented and would probably wind up shaking myself to death was in itself risky, given my history of drugs and depression. To be fair, that wasn't exactly the way she put it. She tried to be delicate, minimal in her description of the symptoms of HD, and ended on the optimistic note that my chances of developing HD were fifty-fifty. Hell, you toss a coin and don't you have just as good a chance for the coin to turn up heads as tails?

She handed me a booklet describing in detail all one would ever need to know about HD, along with a copy of the original paper written in 1872 by George Huntington, "*On Chorea*," his classic two page essay that first described the disease. She insisted that I read the literature. Afterwards, we would discuss "my problem" in depth. There's no way one can sanitize the nightmare of being at risk for Huntington's, an incurable, fatal disease, but then having a father who had HD is not the sort of secret one can keep forever from a son who is also fifty-fifty to one day acquire it.

Devil's Dance Redux

As it turned out, she had correctly evaluated my then innocent, but no longer immature state of mind. I suppose you'd call it a mother's intuition that I was now capable of absorbing this malignant tidbit of information without the sort of psychic breakdown that she feared.

That is not to say that there hasn't been a single day during these past twenty odd years when I haven't given at least a transient thought that one day I might develop HD. These thoughts could pop up at any time, without warning and sometimes in situations when one would least expect to have such dark, foreboding ideations. For example, only yesterday I was examining a patient who was miraculously recovering from a degenerative myopathy and I thought to myself, "How did she get so lucky to be able to beat a disease in which nine out of ten patients wind up in wheel chairs? No such possibility for the Huntington patient." Though, more often than not, my thoughts about HD would occur in the solitude of my bedroom, where not even the tranquil sounds of a Haydn string quartet could drive out the nightmarish sense of plunging into a dark hole, a never-ending abyss in which my diseased body would become weightless and forever remain in limbo during the free-fall.

One would imagine that any reasonably intelligent neurologist, when confronted by the possibility of an incurable genetic disease in one of his patients, would advise him/her to take a simple blood test that would positively identify whether or not the genetic defect is present. In the case of Huntington's, this is determined by an unstable expanded CAG trinucleotide repeat mutation in a novel gene on the short arm of chromosome 4. How then can I answer for myself why I have steadfastly refused to take the HD test, though it has been available since 1993?

Ah, yes, what a glorious day it would be to discover that our family's little genetic flaw has passed me by and that I and any children I might yet sire and their children and their children's children would never run the risk of winding up in a nursing home defecating on themselves.

But my friends, what if that dastardly coin comes up on the wrong side, and I am linked to the knowledge that one day I will wake up and not remember how to tie my shoelaces. It is the uncertainties in life that we dread the most, death being first and foremost, but to know that you will develop Huntington's Disease one day is a close second.

"Take the test, you lousy coward," my friend Jennie Kowalski tells me for the second time this month.

Jennie has a vested interest in whether I am carrying the Huntington gene since we'd been on and off for over five years, and, if I tested negative, she claims she'd agree to marry me. I think she's a bit of a selfish bitch in being unwilling to marry me no matter which way the test goes. But, unfortunately for me, Jennie sees the issue from a slightly different perspective. Being only thirty, she still has an interest in bearing a healthy child, not one who might be carrying a fatal gene on chromosome 4. I contend that if she becomes pregnant, there are these nice little prenatal tests that can determine if the fetus is carrying the HD gene. If we have bad luck, she can abort and we can try again. Since she's Catholic, I've only tried that argument once. After she had calmed down, she was quick to point out that, aside from the immorality of abortion, prenatal tests were not without risk to the fetus.

Valid arguments, yes, but I think that behind my youthful, gorgeous, public defender's pronouncements lie the possibility that she's unwilling to spend a significant portion of her life caring for a husband with a degenerative disease. She has already backed out of our relationship twice, but for reasons that I've never wanted to probe keeps coming back.

"I will take the test," I tell her.

"When?"

"Soon. I promise."

Devil's Dance Redux

“This is *déjà vu* for the hundredth time.”

An exaggeration but not without some justification. I vow to myself that this time I will positively take the test.

This particular conversation took place only two days ago at her office in the courthouse in downtown Newark, moments before she was to appear in court to defend an indigent defendant who had been accused of breaking and entering his neighbor's house. The defendant allegedly suffered from Tourette's syndrome, a neurological disorder characterized by tics, involuntary, rapid, sudden movements and obscene vocalizations that may occur repeatedly in the same way. Jenny has summoned me to be the defendant's expert witness. I am to testify before the court that patients with Tourette's are prone to depression and have a compulsive need for immediate gratification of their desires and, therefore, psychologically cannot be held fully accountable for the sort of asocial behavior, which the defendant has exhibited. This is a bit of a stretch, though it's always possible that her client suffered from an obsessive/compulsive disorder associated with the disease. Jennie is especially interested in obtaining a soft plea bargain for him and decided that I was going to be that little extra that would swing it for her.

“Can we talk about this case?” I ask her.

“I want to know first how soon is soon?”

The woman is like a bulldog. Once she gets her chomps on you, she doesn't let go easily. “Within a month, I promise I will take the test.”

“In two weeks, I'm accepting a job with a law firm in LA.”

“Doing what?”

“Tax and estate planning.”

“You hate that sort of law.”

“But I would love working for Jim O'Reilly, who has been after my ass for years.”

“You're *fucking* blackmailing me.” I am quickly beaten. It doesn't take much for Jennie Kowalski to pin me

against the wall. If she actually flew off to LA, I would have to follow her on the next plane and self-destruct what little dignity I still possessed begging her to return with me to NJ.

“Okay, within two weeks I swear I will take the test, I say with all the phony sincerity I can muster. “Now what about this thug I’m supposed to be testifying for.”

“He’s no thug. He just turned eighteen so I can’t get him into juvenile court. His father’s a no show and his mother works two jobs as a domestic to support her six kids. He went through his neighbor’s back screen door and stole a dart set, a broken wrist watch and an old transistor radio that doesn’t work. He said he wanted to buy one of his little sisters a birthday present and got desperate. If he stands before Judge Kramer and is twitching and shaking away, the judge will think he’s on Coke and give him time, maybe six months or a year. It’s up to you to save this young man.” She checked the time. “We get to see the prosecutor in fifteen minutes.”

“Where’s the patient?”

“He’s still in lock-up. Don’t worry, you’ll have five minutes to exam him.”

Burgess Abraham is a tall, wiry, sullen, black teen whose dark eyes come right at you and ask you point blank: who the hell are you staring at? I could see right off that it is certainly possible that he has Tourette’s with his frequent blinking and self-conscious, nervous demeanor, though I witness no involuntary facial tics or improper vocalizations. Through enormous will power, Tourette’s patients can control these “involuntary” facial tics, in much the same manner as one controls a sneeze. Inevitably the irresistible urge will manifest itself, but the intelligent patient will seek to avoid social contact at that time and thus circumvent any possible embarrassment. I have the sense that Burgess Abraham is such a patient and is aware of his need to repress his symptoms.

Devil's Dance Redux

"Your file says you have Tourette's syndrome," I say to him.

"That's what they tell me at school."

"Do you realize that all that blinking and stuff that goes on with your facial muscles isn't something you can do anything about?"

"Shit, man, you think I don't know that."

"Did you ever see a doctor for treatment?"

"Who gonna pay for it?"

"What about Medicaid?"

He laughs, a cynical, little chuckle. "Last year the school doctor, he makes an appointment for me with some doctor on Ferry Street. I take two buses to get there. When I tell them I'm on Medicaid they say they can't see me and send me to this clinic on Springfield Avenue where there's a hundred people jammed into the waiting room. Shit, you a nigger on Medicaid, you treated worse than a dog."

I hand him my card. "After you get out of this mess, call my office and make an appointment."

He glances at the card and stuffs it in a back pocket. He'll never call me. He thinks I'm playing some sort of white man's game with him. Maybe he's right. I don't recall that I've ever treated a black youth for Tourette's in my Westfield office in the seven years I've been in practice.

"Why did you break into the man's house?" I ask him.

He shrugs. "I ain't no thief."

"But you did it."

"Yeah, I did it. So maybe I'm a *fuckin'* loser."

"Why?"

"I wanted to buy my baby sister Denise a real birthday present. All she been talking about is a doll house she seen in Toys R Us. They maybe cost fifty dollars."

"What you stole isn't worth ten dollars."

"Yeah, ain't I the genius."

As it turns out the asst. P.A. isn't really interested in wasting the court's time with the likes of Burgess

Abraham. Since it is a first offense, he offers Jennie two years of probation for Burgess and ninety hours of community service, which means spending six hours a week for fifteen weeks at one of the local dumps sorting out the trash. Jennie knocks him down to one year on probation and sixty hours of community service and I like to think that my presence had something to do with the prosecutor buckling under without further compromise. A five hundred dollar fine goes along with the plea bargain, which, of course, Jennie makes me pay for, and which Burgess says without asking that he'll pay me back as soon as he gets himself a job.

Yeah, sure. All in all, it is an expensive morning, particularly when you toss into the mix that I had to cancel six patients to accommodate Jennie's work schedule, not to mention my ironclad promise to Jennie that I'd take the HD test within the next two weeks.