BEHIND THE BOOK - *A LITTLE LOVE STORY*

Fifteen years ago, when I first started playing a lot of golf, I resolved that for every time I played I would set aside a dollar for the local food bank. It was a small thing, a gesture to keep me from feeling too guilty about the many pleasures in my life, and the many hardships in the lives of others. This charitable impulse - we give more to other causes - resulted in less than a hundred dollars a year, but it felt right.

Long before I started playing golf I started having back problems: I broke my upper back in a bad fall, had surgery on my lower back for a ruptured disc; all of this was, and is, complicated by a bad inherited arthritis. I saw - and see - chiropractors and massage therapists and yoga practitioners and rheumatologists, and I take pills and give myself shots. I'm fine, really. I can golf and lift weights and walk and bang nails and climb ladders, and I'm always grateful that the fall didn't cripple me and that the pain is small compared to that suffered by other relatives with even more serious types of arthritis.

During my weekly visits about twenty years ago, one of my chiropractors - a friend, really - would often tell me about his three daughters. They all sounded so bright and wonderful that I have to say, as someone who had not yet known the joys of fatherhood, I was sometimes jealous. And then one week the story changed radically: he and his wife had discovered that their oldest girl, who'd been coughing for ten years, had been misdiagnosed all that time. Their new doctor had done some tests and discovered that the girl actually had, not allergies or sinus issues, but something called cystic fibrosis. More tests revealed another terrible piece of news: the youngest girl had CF as well.

I'd heard of the disease, but only vaguely. My friend filled me in: it was caused by a genetic glitch that resulted in dehydrated mucus. That seemed a small thing, but it turned out that sticky mucus led to bad lung infections, and often to reduced function of the pancreas, and that, at the time, the life expectancy for people with cystic fibrosis was in the high twenties. He and his wife, naturally, were in a state of shock. They'd begun researching the disease, taking their daughters to the nearest CF center - an hour away - doing a daily regimen of chest physical therapy that involved the parents drumming on the girls' chests, sides, and shoulders for 45 minutes at a time. The girls started taking a number of medications, did what they could to avoid colds, changed their diets.

I felt so sad at this news that, in another tiny gesture, I started giving my "golf dollars" to the Cystic Fibrosis Foundation in Bethesda Maryland. (www.cff.org)

Not long after that our own first daughter, Alexandra, was born. She seemed healthy, although we noticed when she caught a cold it seemed to last an unusually long time and often produced a cough that went on and on and seemed better suited to an adult pair of lungs than to hers. Three years later, when Amanda was pregnant with our second child, a genetic counselor asked if our first had been checked for CF. We didn't know. To avoid having Alexandra go through the testing procedure, Amanda and I were first tested: unless both parents are carriers of the defective gene, their children can't have CF.

It turned out we were both carriers (carriers are mostly asymptomatic but can have some sinus and digestive troubles). It was too late in the pregnancy to test the child in Amanda's womb, but Alexandra was tested, and, after a very difficult waiting period, we learned that she did, indeed, have cystic fibrosis.

It was almost as if the conversations with my chiropractor friend had been preparation for that harsh moment. I already knew a lot about the disease and immediately Amanda and I set out to learn more. We started doing nightly chest PT, we started keeping Alexandra away from kids with colds, we started doing the fundraising walk every spring, and our friends and relatives responded with a generosity that often brought us to tears.

I won't go into all the medical details here; there's plenty of information online for those who are interested. But I began to write about CF, both in an attempt to learn more about it and to increase awareness. I wanted more money to be raised for research, and I didn't want any more parents to be blind-sided the way my friend and his wife had been.

I published a piece in the *Philadelphia Inquirer Sunday Magazine*, and then a longer one in *Readers Digest*. I spoke to doctors and patients, interviewed family members and caregivers, and read whatever I could find on the subject. Of all these interviews and articles, the one that hit me most powerfully was a phone conversation with a young professional woman with cystic fibrosis. Like most people with the disease, she was stoic about the sometimes grim and always inconvenient treatments, about the breathing troubles, the recurrent infections, the hospital visits to "clean out" the bad colonies of bacteria in her lungs, the digestive issues, the enzymes with every meal, the worry that she'd be infected with a virulent strain of B-Cepacia and her condition would quickly grow worse. She was even at peace with one particularly horrible aspect of cystic fibrosis - that sufferers should not be within an arm's length of each other for fear of passing along one of the long list of bacteria that present no danger to the rest of us, but can gradually destroy the lung tissue of someone with CF.

She was typically without complaint about those things, but what bothered her - and I could clearly hear the pain in her voice - was the social aspect of the disease, the fact that, as she put it, "I'm not a good long-term investment," so guys were happy to date her, but unwilling to enter into any kind of serious relationship.

I could not keep from imagining my own daughter in her situation.

My books always come from what I think of as "my center". I don't write at arm's length, don't decide to research subjects out of intellectual curiosity and then write books about them (not that there's anything wrong with that; it's just not how I operate). I write, almost always, about what I really care about, and since cystic fibrosis was continually on my mind, I decided to write a novel about it.

The article in *Readers Digest* had been about a young man in San Diego named Matt Joyce, a passionate and expert surfer, whose life had been saved - 'extended' is a better word - by the generosity of two men, one a complete stranger. Each of them donated a lobe of their lungs - one

from the right lung, one from the left - so that this young man's ruined lungs could be removed and he could keep breathing. The surgery - it's called a 'living lobar transplant' and is performed only about fifteen times a year in the US - worked, and when I saw Matt he was at the beach, on his board, and looking fine, I used that surgery in *A Little Love Story,* and created a situation in which the woman had an advanced case of CF but the man was committed to her anyway.

I'll say no more about the plot, and certainly not about the ending, except that I didn't want to write some kind of Hallmark Card finish to the story. The first few pages of the novel are actually its ending. Some readers have been confused by that, some bothered; many like it. But I wouldn't change the last line of the book for anything.

During my tour for the novel, after a reading/talk at Baker's Books in South Dartmouth, Massachusetts, a beautiful young woman came up to me and said she had CF and had driven an hour to thank me for writing the story.

Alexandra is 17 now. She's had three sinus surgeries and a myriad of other troubles, but she is leading a life that is very close to that of a healthy young woman. Her boyfriend, a young man from Italy, a first-class guy, seems, almost as if he stepped out of the pages of *A Little Love Story,* completely unbothered by her sometimes persistent cough and the various changes she's had to make in her life because of CF.

Juliana, tested shortly after birth, is a carrier, like her parents, and very healthy. My friend's daughters - both of them with more serious manifestations - are doing well, but they have suffered mightily over the intervening years, and the stress on the parents is not measurable. The life expectancy of people with CF has jumped ten years since Alexandra's diagnosis, and new medications promise, if not a cure, then at least a treatment regimen that will make life much more bearable for the 70,000 people worldwide who suffer from what is truly a vicious disease.

My heart goes out to all the CF sufferers and to their families, and my thanks and thoughts to the researchers and doctors and respiratory therapists and social workers and dietitians, and everyone the disease has touched in any way. May its impact be reduced, even eliminated in some lives, by the time another summer has given way to fall.

That concludes this month's tale. I remain grateful for your interest.