



SARA AND THE GIFT OF LIFE

PROLOGUE

I lay stretched out on the operating table, mercifully anesthetized and intubated, attached to a heart-lung machine—my chest and abdomen split open into a glistening chasm of tissue and bone. Blood-soaked plastic tubes, sponges and clamps are strategically placed within my frail torso. Considering my youthful, female modesty, this is the ultimate exposure, going deeply beyond the surface of my naked self. Some of my heparin-thinned blood pools in my body cavity and is quickly suctioned back into the heart-lung machine's pump. My blood is precious to me and I prefer not having a single drop wasted even though a large blood bank withdrawal has been made on my behalf.

When the surgical nurses rolled me into the operating room my face and body were noticeably cyanotic. Now, I am a pallid, zombie-sort-of grey, resembling a cadaver without the rigor mortis. My protein-starved, muscle tissue has wasted away, causing my body to appear malnourished, as if I were anorexic, which is hardly true. I am always hungry. My legs and feet are so swollen from edema, the fluid leeches out of my pores like sweat and the tension on my skin has busted thousands of capillaries, creating bizarre blotch patterns. My abdomen is so full of ascites fluid it makes me look nine months pregnant.

Before the surgeons carved me open with their scalpels, they stabbed a catheter into my left flank to drain the fluid or it would have gushed out onto the floor. Eight liters is enough to make quite a mess. Up to this point, I've endured a record-breaking 186 of these paracentesis procedures to alleviate the pressure on my internal organs and to prevent further abdominal wall herniation. Already, my

navel had to be surgically removed. It looks pretty weird having a stomach without a belly button. If you include all my other surgical scars, I'm not a pretty sight at all. It's awfully hard on a 19-year-old girl's self-esteem.

My heart and liver are both in failure. In fact, those vital organs are being painstakingly sliced out of me to be transplanted with healthy ones, harvested from someone who died only hours ago. Most likely, my donor organs came from the victim of a car accident, or a gang member who was shot in the head by someone in a passing car as he stood on the sidewalk rapping with his homeboys, or maybe it was a teenage skateboarder who flipped and broke his neck. My new organs might even be from some innocent person killed by a terrorist bomb. The world and my life in it seems so insane and complicated, it hurts my head just thinking about it.

You know what? I don't want to know anything about the person my new heart and liver are coming from, at least not right away. I mean, it's strange enough just having someone else's organs replacing my own without wondering about the donor's age or gender. Don't get me wrong; I'm extremely grateful for this ultimate gift that will save my life and hopefully improve the quality of it in ways I only dreamed could ever happen. First, I need to survive all the cutting and not bleed to death.

The surgeons from the heart transplant team are already methodically grafting in my new heart while their colleagues from the liver transplant team anxiously wait their turn. Their blood-spattered scrubs and plastic face shields, silhouetted by intensely bright, overhead lamps, render them unrecognizable. Only the solemn glare emanating from their eyes, give them away as human when they seem to appear more like probing extra-terrestrials.

I don't want these masked surgeons to contaminate my body with anything, not a single germ nor a single strand of hair—nothing. Any infection that comes along now would do me in, especially with all the powerful anti-rejection drugs that I'll have coursing through my veins to suppress my immune system. It annoys me just imagining the possibility of a sweat droplet falling from a surgeon's forehead into my body's gaping cavity when he tilts his head forward. And please, no coughing, either. The plastic, face shields prevent all this from happening so my concerns are actually rendered moot. Since I'll be hanging out at death's door for the next sixteen hours, any paranoid thoughts seem meaningless right now.

Suddenly, my mind implodes into its own personal black hole, trapped somewhere between delusion and hallucination. I don't know which, if either. Did

the anesthesiologist up the ante with more powerful drugs? I envision myself as an Egyptian princess (cool) being prepped for mummification (not cool) by a couple of bald-headed priests as if I had slipped through the boundaries of time. That vision rapidly fades away, replaced with a sublime feeling of being suspended in some sort of dimensional limbo, somewhere, yet nowhere.

I can't be in a dream state this far under the influence of drug-induced sleep and comatose. Are my neurons misfiring inside my hibernating brain or is it my spirit manifesting itself? Will I stay alive or reach out for the hand of God? I'm in an endless void, floating and spinning without direction. I move my arms and legs, dog paddling to get back to my body, but I cannot. I am drifting downward and inward into infinity or is it upward and outward? I can't tell. I have no reference points, only a blackness devoid of light.

Everything becomes still and peaceful. I'm in a state of suspended animation. Blurry visions now begin returning to my dormant brain, passing in slow motion. Dolphins leap, twist and turn, chasing spots of light that look like streaking meteors. Stars, like the uncountable souls of every living creature that has ever lived, fall into monstrous, gas nebulae and disappear. All this pure thought energy seems beyond my physical self. Is it genetic imprinting passed over generations or some kind of cellular memory? Is it psychosomatic or the work of out-of-whack neuropeptides? No neurosurgeon is giving my brain any kind of consciousness enema, either. I am an echo of my physical self, a manifestation of what may even be spiritual. Is this some kind of enigmatic craziness or a sign that my soul is defective? Do I even have a soul? Can souls be defective? My body is already broken enough. I don't need a broken spirit as well. Not a good thing.

At last, my brain resonates with the sound of intermittent voices. Are the surgeons finished? I'm still alive. Holy crap, how did they pull this off? Closing in on the physical reality of time and space, I pick up, in between the medical-technical jargon, some of what the surgeons are saying about me. They describe me as brave, talented and sweet. One of them mentions an abstract painting I presented to him a few weeks ago and how it symbolized my chronic pain. I fervently disagree with most of what they say. My best artwork is more the result of serendipity than anything else. I weep and moan when in pain, try to hide from adversity whenever possible and I'm just as much sour as sweet.

1. A TUMOR AND A FETUS

I broke out into this world via cesarean section, two weeks premature, adding one more number to an overcrowded, world population of over 5 billion. If I could have remained within the relative safety of my mother's womb for 18 more days, I would have been born on Christmas day, but I blew it. I was competing with a vile, ovarian tumor for a bit of space and I lost the fight when her water broke. My multifarious life began when that monstrous tumor caused me to be evicted from her belly on the anniversary of the attack on Pearl Harbor, December 7, 1983, my personal and insignificant day of infamy.

In spite of being cyanotic and symptomatic for congenital heart disease, I was never evaluated any further than having a cold stethoscope pressed against my tiny chest. The attending physician detected a heart murmur, but it was deemed inconsequential and since my mother was in immediate danger of losing her life, I became sidelined to the hospital nursery while they surgically removed the tumor. Once that mass of out-of-control cells had been dissected out, she underwent a complete hysterectomy and lost quite a lot of blood.

My father, a somewhat disgruntled, ten-year veteran, border patrol agent, who vehemently resented the national politics that undermined the morale of his fellow officers, took an emergency leave of absence to be with his beloved wife and newborn daughter. He was awful scared when he found out his new baby girl had a tumor subbing for a twin and, even worse, knowing that his wife might die from hemorrhaging. There is something profound about seeing a big, muscular man become misty-eyed. My three-year-old brother riding on his shoulders was blissfully unaware of his terrible fear.

After four days, Mom recovered well enough to be transferred out of the Intensive Care Unit, much to Dad's relief. Even though she shared her new room with an overly obese woman with a fractured skull who resembled a beached, humpback whale, it was wonderful that we could all be together for the first time. First time for me, anyway.

I bawled and wailed incessantly like a holy terror for the entire four days I spent in the nursery until a nurse with bouncing breasts brought me to Mom and placed me in her waiting arms. At last, I shut up. A tear ran a tortuous path down her cheek. I wasn't sure if it was from her finally getting to cuddle me or because she sensed something about me was terribly wrong. The jiggly-breasted nurse explained to her that I had a heart murmur, most likely caused by a small hole in the septum that would eventually close by itself in time. This diagnosis and

prognosis came without any tests being done. There were multiple reasons for this.

Los Gabachos Hospital, located in a border town of the same name, had more experience dealing with gunshot and knife trauma than pediatric cardiology. Emergency medicine was the mainstay of the hospital's existence. Maimed and bleeding victims came in from both sides of the United States-Mexican border. The hospital also represented the ethnic and economic pulse of this backwater of a border town, which owed its existence solely to being a portal between two countries that began as a horse trail many decades ago. It was a sun-baked, desert crossing between two different cultures and languages, 300 miles south of the nearest major city.

A scruffy old priest from an adobe church with crumbling walls across a dusty side street from the hospital visited Mom every afternoon. I think his name was Father Domino, or something like that. He actually spent more time in the hospital than at his pulpit, often giving last rites in the ICU. So many people died there, the nurses called it "God's waiting room." Mom was a devout Catholic and she felt better praying with the priest while my agnostic father bowed his head out of respect for her feelings and said nothing. My brother just leaned on the edge of the bed and stared at me with wonder in his eyes, oblivious to the praying.

Another week passed and Mom was able to get out of bed and move about the room. The obese lady had been discharged days before and the room was all to ourselves. I heard her laughing and my brother giggling, and their joy was infectious. My toothless, little mouth formed itself into a circle to let out my own happy sounds. Mom was extremely fortunate to have survived much to the credit of the surgeon who operated on her immediately after my birth. The ovarian tumor was deemed a stage IC and she refused chemotherapy. She was lucky. Never again did any signs of cancer show up.

My situation was quite different. Without surgical intervention, I would die in a few months. After leaving Los Gabachos Hospital, Mom and Dad, concerned about my blue-tinted lips and fingernails, took me to see a pediatrician in Oakden, that major city 300 miles away. After examining me, the alarmed physician had me admitted to Oakden University Children's Hospital (OUCH) where they ran a battery of cardiac tests. They found my heart to be congenitally messed up with tricuspid atresia, pulmonary valve stenosis, and a couple of holes, which were the reason I was still alive. The holes in the atrial and ventricular septum allowed my

blood to flow and be pumped enough to sustain my five-and-a-half pound body even though the oxygenated and non-oxygenated blood were mixing together.

Mom and Dad watched fearfully as I disappeared into the bowels of an operating room for my first heart surgery. I was only three weeks old. It is a parent's nightmare when one of their offspring is critically ill. A suffering child breaks down a mother and father's soul, making it difficult to keep their faith, whatever that faith may be. Feelings of guilt for a child's congenital defect may haunt their minds even when no responsibility or blame exists. It is only the indifference of the nature of life itself, nothing else. In time, my parents will learn and accept this fact.

The surgery, a Blalock-Taussig shunt, was a palliative procedure to keep me going until I became a few years older and better able to withstand the next operation, a major open-heart surgery. Since I wasn't yet too good at describing, much less understanding, medical procedures, I just thought that my cardiac plumbing would be dramatically changed. It was easier to think of my arteries as red pipes and my veins as blue pipes.

I never understood why doctors bring up the risk of death factor when they talk with parents before a child's surgery. There are only two probabilities: possible death during surgery or definite death by doing nothing. The obvious choice is surgery since that at least gives you a fighting chance to survive. Who in their right mind would say no to surgery if you would automatically die without it? Isn't fear of death supposed to be worse than death itself? Maybe, I suppose, some of us are not in our right minds. I survived the B-T shunt operation without any major complications.

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I, Sara Jones, conceived one night, as my mother and father made love in the sand dunes under the gaze of a full moon in the desert sky, want to live. Adversity shall make my spirit strong enough to sustain my physical body. I shall defy nature's survival of the fittest law. I am special to myself and living will be my destiny. Besides, I want to ride on my father's shoulders just like my brother.

2. FIRST OPEN-HEART SURGERY

At the age of three, I was being prepped for my first open-heart surgery at OUCH. Being a toddler, I could not understand the significance of such an operation, although, I could sense the nervousness Mom and Dad felt and that frightened me to tears. My emotions were heightened further when I saw a

blood-sucking phlebotomist approaching to draw my blood. I had already developed a powerful phobia about being stuck with needles and my skinny, little arms, with their itchy-bitsy veins, quickly retracted behind my back. “Dad-eee!” I screamed.

While Dad cushioned my bony little body in his powerful, yet gentle and loving arms, I submitted to the torture of becoming a human pincushion once again. This blows away the theory that fear is stronger than love, in my case anyway. Why, oh why, did I have to be so young, with such a limited vocabulary, just when I could have really used a good expletive? Fortunately for the unsympathetic vampire lady, I was unable to yell, “Stop bitch!” I could tell from her glaring eyes that she didn’t like her job very much. Sticking needles into the arms of immature, little people all day could not be any fun.

I was already in the operating room when my IV was put in. I must have, somehow, been given a potent analgesic, since I don’t remember it hurting at all. Whatever they gave me was conveniently never recorded in my chart, most likely because it didn’t conform to pediatric treatment protocol. The IV was surgically inserted above my left wrist by a “cut down” procedure and held in place by sutures. Within seconds I was in a deep sleep, my favorite part of any surgery.

Doctor Manos, my cardiothoracic surgeon, insisted on doing the IV himself, not trusting anyone else to mess with my delicate veins. He had huge hands for a surgeon, yet his expertise and manual dexterity with a scalpel made him legendary within the local medical establishment. That is, unless some extenuating circumstance came into play. There may be only one way to enter life, but there’s a whole lot of ways to leave it.

Doctor Manos created a passageway that let my oxygen-poor blood from my body bypass my heart and go straight to my pulmonary arteries. My right ventricle wasn’t required to pump the blood into my lungs, allowing my oxygen-poor blood to passively go directly to my pulmonary-artery circuit without needing to first enter my abnormal heart. Oxygen-rich blood then returned back to my heart to be sent to my body with only a small amount of oxygen-poor blood mixed in. This surgery effectively rerouted my cardiac plumbing.

Near the end of my operation, a low rumbling sound began reverberating throughout the hospital. The walls in the OR groaned from stress. IV poles, gurneys, monitors and everything else began shaking and swaying. Doctors and nurses froze in their tracks for a second, gawking at each other. They stared at the ceiling, the walls, the vibrating gurneys and the exits. A female voice shrieked, “Earthquake!” The temblor only lasted for three or four seconds and stopped.

Everyone remained frozen, anticipating an aftershock. There was none. They quickly closed up my chest and transported me to the Pediatric Intensive Care Unit.

Dr. Manos saw Mom and Dad right away to let them know my heart surgery went well. He told them there was a separate problem they were working on that he was quite concerned about. The tip from the catheter monitoring my heart broke off and became lost in my bloodstream.

“Can you find it?” Dad asked. I’m sure a sharp pang hit him in the gut. “Is it life threatening?”

“Mr. Jones, we’re x-raying her right now and we’ll keep x-raying her until we find it. Once it’s located, we’ll surgically remove it. It’ll be lodged in a blood vessel. We just don’t want to find it in a bad place.”

Mom thought the earthquake caused the catheter tip to come loose. Dr. Manos told her that was a very unlikely scenario and apologized even though he bore no fault. When the doctor left, Dad whispered in her ear, “I hope those shadow-gazing radiologists find the damn thing. It better not have gone into Sara’s brain!” He was not a happy camper. Mom automatically began praying.

Fortunately, I was never awake during the “great hunt for the missing catheter tip” ordeal. After enough x-rays were taken to deep-fry my body, it was finally found, stuck in a vein in my left leg near my knee joint. I was hustled back to the OR to have it surgically removed. I don’t know why removing something that small required a seven inch cut on the inside of my leg and another four inch cut next to my ankle. Go figure. My scar collection was off to a fantastic start.

The rest of my hospital stay was uneventful, except for an incident when my favorite stuffed animal, a fluffy white kitten, became lost when a laundry worker rolled it up with the sheets during a bed change. When it couldn’t be found in the laundry room after an extensive search, the hospital bought me a replacement, more to pacify me than to atone for the mistake.

After a few days, I became bored. What can a toddler like me do to make trouble or cause something to happen that creates a good effect anyway? Not much. I’m still too young to have much of an adventurous and fascinating life unless you count something trivial like regurgitating chocolate candy. I managed to do just that while being held and coddled in the playroom by an unsuspecting, hospital volunteer with watermelon-sized breasts who just had to grab me in her flabby arms and declare what a cute little angel I was. After launching my warm, vomit surprise into her cleavage, I’ll never know why she didn’t immediately fling

me into the nearest trashcan. She must have had a very powerful maternal instinct to put up with that kind of thing.

I unwittingly began to gather my own personal, empirical evidence that the larger a woman's breasts were, the more maternal she was. Conversely, I had yet to be picked up and hugged by any thin, hard-bodied women. No offense meant to all the beautiful ladies in the modeling industry.

As long as you were not getting stuck with needles or forced to drink yucky fluids, hospitals can sometimes be fun places for kids. My brother pushed me all around the pediatric floor in my wheelchair, laughing and laughing, almost colliding with people in the corridors, while Mom and Dad ran after us fearing an imminent accident. Pediatric wheelchairs are way more fun than little red wagons and tricycles.

Even the first time I went to have a CT scan was fun. I had to remain perfectly still while I slid into that big metal doughnut. The radiology technician was nice and smiled at me a lot. So did the nurse. She said I would be much better than before and told my parents my fingernails and lips will always appear a little bit blue. She called it "Smurf sign." The nurses had cool names like that for everything. One of the medicines I had to drink was called bug juice. How could I not drink something called that?

3. UNDER THE KNIFE AGAIN

I now saw the world through the eyes of a precocious 6-year-old, still trusting adults who were making life-defining decisions on my behalf. It will be at least eight more years before I figure out that life isn't fair and my place in this divided world will be determined only by my own volition. A few character traits have started to manifest themselves, which will either help or hinder my development into whatever I decide to make of myself, once I grow up. I was not too sure I wanted to grow up, though.

With the exception of my menacing congenital heart defect, I was blessed by inheriting some pretty cool genes from my parents. Mom gave me a beautifully sculpted face with charismatic eyes and a million-dollar smile, although I never did like my nose or profile. Dad gave me fortitude, common sense and an adventurous, free spirit. I can credit Mom for my looks and always blame Dad for my actions. Dad was always proud of me no matter what I did, right or wrong. Yep, I'm going to end up becoming a bona fide "daddy's girl."

My parents were also immensely proud of my older brother, Tommy. He is a very bright kid with a high IQ, left-brained and analytical, while I am right-brained and supposedly creative. We got along amazingly well without a lot of that petty childhood jealousy. Only once did he get really angry with me for messing up one of his videotapes and I had to take refuge in the bathroom behind a locked door. Other than that single incident, we always enjoyed playing together, giving credence to the “opposites attract” concept.

Tommy noticed a change in my disposition, decided it was because I didn’t feel well and alerted Mom and Dad. Away we went to see Dr. Mutt, my pediatric cardiologist, and soon I was subjected once again to a new battery of tests. One of the holes in my heart had become slightly enlarged, enough to affect the pressure dynamics of my new cardiac plumbing. Another cardiologist at OUCH, Dr. Jeff, would attempt to fix this with a new type of umbrella device using a catheter. He was a real “cath” jockey, doing heart catheterizations on every patient he saw.

The procedure failed and now I had to undergo another open-heart surgery. Dr. Manos would be my surgeon once again. I liked his Santa Claus smile and kind eyes with the crinkly wrinkles encircling them. Besides Dad, he was an adult I especially trusted, unlike inexperienced surgeons who tend to fatten graveyards.

It isn’t necessary to bore anyone with more abstruse details of my early heart surgeries so let me just say Dr. Manos kept his reputation intact with another successful opening and closing of my chest. His skill in manipulating a scalpel with those huge hands of his was a piece of cake, or should I say, a piece of flesh? After the surgery, everyone was smiling—my parents, doctors, nurses, and clinicians, even the housekeeping staff. Not me. I just tried to focus through glazed eyes and thought some childlike equivalent of “What the hell?”

Once out of the “torture room,” more familiarly known as the PICU, and disconnected from all the drain tubes, I was able to wiggle around a bit and get a little more comfortable. Lying in one position too long can give you bed sores. Now I could eat vanilla ice cream (why don’t they ever have chocolate?), watch cartoons, play video games and be pushed around in a wheelchair by Tommy. You could hear us laughing and giggling all over the pediatric cardiac ward as we raced around. Most people enjoyed seeing our happiness, but a few meanies frowned at us with pissed off looks on their faces.

During the evening Dad would tell me stories, both real and imagined. I always pressed him to make up tales about cats, which turned out to be so incredibly stupid it made Tommy and I laugh hysterically only for that reason.

When he talked about the things he saw and did in the days before he married Mom, I would watch her reaction. If her eyebrows turned down toward the bridge of her nose, it meant she really didn't believe what he was saying. If her eyes rolled, it meant Dad was lying his ass off. When her face remained stoical, it meant she had no clue if what he said was true or not. Most of the time, she wore that particular, clueless expression.

Before he became a border patrol agent, Dad was a firefighter and before that, a longhaired, chopper-riding biker. He avoided talking about his motorcycle days until we kids were older and he never did so in front of Mom. I refused to believe his firefighting stories even though he insisted it was the truth. How could an airplane mistakenly drop borate on the fire truck my dad was riding in, turning it from red to white? How could a bulldozer, grading out a firebreak up on a hillside ridge, dislodge a boulder, causing it to roll down and stop right smack on top of the fire hose my dad was holding, cutting off his water supply, forcing him to run away from the flames? Yeah, right.

On the last day of my hospitalization the nurse filling out my discharge papers, overhearing Dad telling me how he rescued a cat being chased by one of those dogs that looked like a wiener with legs, could no longer contain her curiosity. To her mind it seemed highly unlikely for a big, strapping border patrolman to romantically connect with a Mexican senorita.

"Mrs. Jones," she asked nonchalantly, "How did you meet your husband?"

I detected a little, shit-eating grin on Mom's face as she answered the nurse's question. "I have a sister who worked in an auto parts store where Rusty used to buy parts for his jeep and she told him about me. She even showed him one of my photos to get him more interested." Mom always enjoyed explaining how her sister played cupid. "Anyway, the next time I flew up here from Guadalajara to visit her, she invited Rusty over so we could meet. It was love at first sight and we ended up going to Las Vegas that evening to get married without telling anyone."

"Really? You got married before you hardly even knew him?" The nurse looked incredulous. I noticed that she had no interest in me at all. No large breasts, either.

Mom looked straight into her wider than before eyes and replied, "It was not a whim or a gamble. I just instantly knew—instinctively. Rusty was my soul mate."

Dad looked over at the nurse with a confirming smirk. The nurse looked down at her paperwork and whimpered softly to herself, "Sweet Jesus." I'm pretty sure she was single.

4. RATTLESNAKES AND COYOTES

A few months after my discharge from OUCH, Dad was transferred to a vehicle inspection station north of the border and we moved into a rickety, splintered cabin on five acres of boulder-strewn land surrounded by chaparral. The access road was a truck trail once used by the Forest Service, which became impassable when it rained. The steep trail zigzagged one mile to the 4,000-foot apex of a granite hill, starting out from a paved county road, effectively isolating our new habitat from any vehicle without four-wheel drive.

At first, Mom went nuts from the solitude. Then one evening, her face glowing from the sporadic flashes of light from the fireplace, she said reflectively, "It's so beautiful here, so peaceful. I feel God is watching over us." Winter, her favorite season, brought early morning shrouds of fog that fingered their way through the rocks and, sometimes, snow would blanket the ground like powder sugar.

Mom had fallen in love with her new environment and became attuned to seeing and hearing all the things that city life had eroded away from her senses. She breathed clean air, which became crisp and cool in the evening. Myriads upon myriads of stars lit up the night sky. Strangely shaped rock formations, created millions of years ago, along with spindly-limbed manzanita trees, cast magical shadows across the ground.

During the day, scrub jays spent most of their time in the thick chaparral chattering noisily, while a bevy of nervous quail preferred scratching the ground under the watchful eye of a lone lookout perched on a nearby boulder. Circling overhead, crows scanned for carrion, sometimes ganging up on an intruding hawk to chase it away. Ground squirrels and pocket gophers slept the day away deep in their burrows, hoping not to be discovered by a marauding snake.

Early in the night, sounds of coyotes filled the air with short, high-pitched yelps and long howls. Their music overriding the cacophony of insect noise until, at last, all became quiet and tranquil. Only the soft rustling of dancing leaves could be heard whenever the wind wafted its way through the tree branches.

In spite of being enchanted with nature at our little sanctuary, it was something we quickly learned to respect. The brilliant, pastel colors of sunrise

could suddenly change into massive, gray-black thunderheads, unleashing torrents of rain, hailstones and lightning. Brush fires sparked by lightning bolts, were always a major concern during the summer months. Most of the year the weather behaved itself, but many of nature's wild creatures living close by did not. Rattlesnakes did their best to avoid contact, although sometimes it was just plain unavoidable. Wasps, tarantulas and scorpions were unyielding if anyone got in their way. We never ventured outside barefoot and never put on our shoes without shaking them first. Bites and stings on the feet can be unpleasant.

We had a diesel-powered generator with a bank of ten heavy-duty, 12-volt batteries for electricity, propane for cooking and a septic tank. Even cell phone reception was fine at our elevation. What more could we want? Television? Yep, we had a satellite dish, too, although the TV was rarely used. Tommy and I divided most of our time between home school study and living a Tom Sawyer and Huckleberry Finn life style.

When I wasn't playing hide and seek with Tommy in the crevices between the rock formations and boulders, my favorite pastime was capturing all the animals I could find. Dad constructed cages for my menagerie, which included mostly birds, reptiles, and insects. I never could trap anything as wily and cunning as a fox or a squirrel. The only mammal I ever managed to catch was a field mouse. I put it in a cage with Robert, my pet rat. The next day I found it bloodied and dead. Robert had killed it.

Insects were always the easiest to catch. They always fascinated me with their strange, alien appearance, but mostly I gathered them up to use as food for my captive reptiles. I just used a net or clamped a jar on top of them. My reptile collection was made up lizards, snakes and horned toads. They seemed to be everywhere. Horned toads were camouflaged making them hard to see and easy to step on. I always called them "horny" toads and wondered why they were called toads when they were actually lizards. All the other lizards were fast as hell and catching them was mostly a matter of luck. Snakes could only be caught when they were out in the open. I just picked them up behind the head or held them by the tail at arm's length. I did get bitten a few times, once witnessed by Tommy. I chuckled at his aghast expression as he trotted off to tell Mom. Though there were a lot of them around, I never tried to mess with rattlesnakes. If the rattler didn't kill me, Dad may have done so by scolding me to death. He was adamant about Tommy and I staying away from poisonous snakes.

Some of my animals came from pet stores. I loved looking at all the creatures they had for sale. Dad literally had to grab my hand and drag me out

when it was time to go home. The tropical fish, with all their bright colors, enthralled me as they darted around the fake water plants. The problem with having fish, though, is that you can't hug and cuddle them. Also, you needed to take care of the aquarium and I really hated to clean things. Even worse was taking care of birds, the biggest mess makers of all. Lizards and snakes were the easiest caged critters to care for as long as you kept them from getting cold.

I had an anole lizard named Ed who liked to get in my hair. While putting him back into his cage, I closed the hatch on his right front leg, crushing it. I was mortified and began crying. The next day the little guy's leg was swollen and infected. I thought about how all the animals were able to handle intense pain so quietly. I took a capsule of amoxicillin, opened it and sprinkled some of the powder all over a cricket, which Ed ate in one gulp. A few days passed and the anole's leg had withered away and he was fine. My three-legged anole never did climb in my hair again.

I adore cats and had three tabbies. Since coyotes would kill and eat them, they were kept in the cabin at night to give them a better chance at survival. Even during the day cats can get into unexpected trouble. One day, my favorite cat, Ninja, faced off against a bulky, six-foot rattlesnake. The rattler was coiled, tail vibrating and ready to strike. Ninja held her ground, hissing and snarling. Dad wanted to protect my cat even though he didn't really want to kill the snake. If Ninja hadn't been involved he would have caught the snake and relocated it far from our home. At any moment, the cat might move in too close and be struck with needle sharp fangs injecting a fatal dose of poison. Dad took careful aim with his 30-30 rifle and squeezed the trigger. The noise from the exploding cartridge was deafening. Ninja leapt four feet straight up and disappeared into the brush. The bullet tore the snake's head off. With that large caliber it was very much overkill. It was horrible to see a snake killed even to save my beloved kitty. I will never forget the incident.

As I grow older, I will understand more about death and dying, and learn when it is okay and when it is not. When mankind is involved death is almost always wrong. Murder and war are testaments to that undeniable fact. When nature is involved death is right only in the sense of indifference. When an animal kills another animal to eat and insure its own survival then that kind of death is normal. Life cannot exist without death. They go hand in hand. Mankind balances out his violence trying to save lives by fighting disease or rescuing others from harm. Sometimes we care, usually we don't.

5. SCAVENGER LADY

I wasn't the only one living up on our hill who liked cats. About a quarter mile away from our place, hidden from the truck trail behind a wall of granite boulders and thick chaparral dwelled a woman named Dina. She lived like a Neanderthal on acreage owned by some relative whom she never saw. Her age was hard to determine with skin that hid under a crust of dirt and dark brown, serpentine strands of hair that resembled a snake-headed Medusa. I estimated her age at about thirty. Her destiny seemed preset, to live out her life alone, independent as the plethora of feral cats surrounding her encampment.

Dina was a scavenger, a collector of every piece of junk she could find, either from trash bins, alongside the road or from opportunistic stealing. She constructed a hovel-like shelter to sleep in out of pieces of furniture, broken drywall and torn canvas. Surrounding her habitat was enough scrap and trash to resemble a mini-landfill. Next to a beat up, four-wheel-drive Bronco II sat plastic barrels and disintegrating, cardboard boxes full of aluminum cans. There was a large woodpile covered with a tarpaulin held down at the corners with heavy rocks. Bricks, stones and sand encircled a space on the ground where she made fires for cooking.

Tommy and I discovered Dina's hideaway while exploring a footpath once used by illegal aliens trying to avoid "La Migra" as they traversed through our sparsely populated, backcountry area. We found a hiding place in a rock crevice where we spied on Dina, thinking we wouldn't be seen. She had lots of cats, lots and lots of cats, more than I had ever seen at one time. Several of them stared at us.

"Look Tommy," I said excitedly. "Look at all the cats. Must be a hundred of them!"

Tommy spotted Dina near a chicken coop and whispered, "Be quiet. She'll hear you."

Dina pulled a squawking chicken from the coop and held it by the head, flinging it around, twisting its neck until it broke. Clutching a hatchet in one hand and the ruffled chicken in the other with her long, spidery fingers, she lopped off the hen's head with one powerful stroke. The headless body flopped on the ground attracting an army of hungry cats who viewed the event as intently as a silent audience watching a Phantom of the Opera murder scene. After plucking out the feathers and cutting away the parts she didn't want to eat, she tossed the meat into a steel pot of boiling water suspended over a crackling fire. The rest

went to whichever cats were fast enough to beat the others to it. Tommy and I were frightened enough to run away, but for some stupid reason we didn't.

Dina disappeared behind a rock and we temporarily lost track of her until we heard a raucous, female voice behind us. "What er ya kids doin' here?"

"I, uh, I wanted see your cats. I love cats," I said meekly. Tommy stayed quiet, afraid to look at up at her.

Dina hesitated from speaking for a moment as if in thought then continued, "I guess ya mus' be okay if ya like cats. I hate dog people. Where ya live?" Her voice became quieter, but still sounded cancerous.

"Over there," I said, pointing.

"Is yer dad border patrol?" Dina asked. She had often seen his patrol unit parked next to our cabin.

"Yes, ma'am."

"Well tha's good, real good. I guess tha's why there ain't no illegal aliens comin' through here lately. They steal my chickens and cats to eat 'em."

"What? No way. People don't eat cats," I said.

"Yep, they do if they're hungry enough. Dogs, too. Got more meat on 'em than cats do. People even eat people if they're starvin' enough, unless they'd rather die themselves." Dina's face contorted in an attempt to frighten us. It worked on Tommy. He almost started to cry.

Even though I was still a child, I knew the subject needed to be changed for Tommy's sake if not my own. I asked Dina why she had so many cats. She explained that they kept all the vermin away and the birds that tried to eat the chicken feed. Unfortunately, they attracted coyotes, which would stalk and devour them like a delicacy. Since the cats were never spayed or neutered they produced a lot of litters, many of them inbred. The predatory coyotes unknowingly controlled the feline overpopulation problem while the predatory cats knowingly controlled the rodent population. A true win, win situation in nature's scheme of things.

In time, Dina welcomed my coming to visit with her and her cats. Tommy preferred to stay away thinking she was a total weirdo who smelled bad. I never did figure out how she could bathe when all she had was a collection of plastic, water bottles for drinking, until it rained. Then she would peel off her musty clothes letting the rivulets of water erode away much of the dirt from her naked skin. She used a latrine behind a clump of thorny bushes enough distance away to prevent odors from stinking up her "living" area, unless the wind shifted. Following the example of her cats, she covered her poop, albeit with a shovel.

At night, she would make her way to the latrine with a flashlight and squat down bare-assed while mosquitoes and moths would molest her without mercy. Scorpions seemed to know that staying away would be in their best interest. I never told Mom and Dad any details about Dina's lifestyle knowing they would ban me from visiting her. To me, she wasn't some hermit-like lady who wanted to drop out from the responsibilities of life. It was more like life wasn't able to have her for a responsibility.

One day while I was visiting Dina, I asked her why her "cigarette" smelled funny. Since getting acquainted with her, I became pretty good at differentiating odors. "It's got medicin' in it," she answered nervously. "Keep it a secret. I don't want to get in trouble if my doc finds out I'm takin' too much of it."

"I won't tell anyone," I said sincerely.

"Especially don't tell your dad or mom. I could go to jail and my cats would die without me. They're my children ya know."

I recognized the angst in Dina's voice and sensed how worried she had become. At my age, I had no way to know that Dad would not have been concerned at all had I told him about her smoking a funny looking cigarette. He would bust a dope dealer in a minute, but never bother someone like Dina who derived a semblance of pleasure from marijuana. It wasn't his style. I also think it had something to do with what I overheard him say once: "A good dog never shits in his own backyard," whatever that meant.

6. FATHER DOWN

I was seven years old when a twinge of fear gripped me like a vise. Mom had just put down her cell phone and tears began streaming down her face. Her voice cracked with emotion as she told Tommy and I that we had to go to the hospital. Dad had suffered a massive heart attack and we needed to go see him right away. I couldn't fathom how someone with his strength could go down this way. It made no sense to me. For a kid, I knew something about congenital heart disease from my own situation, but nothing about clots and blocked arteries.

Hardly able to see through our tears, we scrambled into Mom's Jeep station wagon and headed down the trail. Mom's driving always made me nervous and now, with her mental state impairing her coordination, being in the Jeep with her behind the wheel was downright dangerous. We bounced sideways when she hit the ruts and slid back and forth in our seats when the frame bottomed out, shaving away any exposed rocks.

“Mom!” Tommy and I screamed in unison. “Slow down!”

After we made it to the paved county road, the rest of the way to the hospital was uneventful for the most part. A few ignored stop signs at empty, rural intersections and a railroad crossing that could not be ignored with a diesel locomotive approaching. Mom hit the brakes and we screeched to a stop just a few feet from the tracks. The RR guardrail rested on the hood of the jeep, red lights flashing their ominous warning through the windshield into our terrified faces. The train rumbled past us like a monstrous, dragon serpent, missing us by inches, its noise drowning out our screams.

At Oakden University Hospital there were enough Border Patrol vehicles scattered about the parking lots to make people think a raid was in progress. My Dad’s best friend, Agent Rainey was waiting for us at the main entrance.

“Hi Vicky...Rusty’s in the ICU now. It looks like he’s going to make it. Luckily it happened during briefing before we went out in the field. We ran code and got him here in time,” he explained to Mom with great relief. “The ER doc injected him with some kind of clot busting drug.”

The waiting room outside the ICU was crowded with uniformed border patrol agents all wanting to see Dad before returning back to duty. I thought it was really cool that my dad had so many friends. Like all law enforcement agencies, their sworn officers are like a family. Agent Rainey picked me up and carried me in to see Dad with Mom and Tommy. We weren’t allowed to stay more than a few minutes, more than enough time for us to give Dad a kiss and tell him we loved him. He remained silent, but his smile told us he would be back with us soon.

And he was. His heart attack involved his left anterior descending (LAD) artery, also known as the “widow maker.” In time, his heart would develop collateral arteries to surround and feed his scarred, heart muscle with oxygen. They performed an angioplasty, put him on an exercise rehabilitation program and gave him various drugs.

Six months later, Dad had another heart attack at home, which he described as very minor compared to the first one, which he said felt like an elephant standing on his chest. Mom drove him to the emergency room, obeying the traffic laws, while Dad popped a couple of nitroglycerine tablets under his tongue. A second angioplasty was done. If these procedures had been performed a year earlier, his heart attacks would have been prevented, but there were no signs he was in trouble. While still in the hospital, Dad began fainting from ventricular tachycardia, an often fatal type of arrhythmia. They put him on

powerful drugs to control the v-tach until, finally, an implanted cardioverter defibrillator (ICD) was surgically placed in his chest.

Now, rehabilitation and returning to work would be out of the question. No longer fit for duty, Dad was medically retired, his career ended and we would be living with less income from his disability pension. Mom worked at odd jobs whenever and wherever she could. At the time, Dad was pretty despondent so Tommy and I did our best to make him happy and soon he snapped out of his depression and became a super father, teacher and our protector. Yeah, we were really good kids.

Later, when my own health turned horribly worse, Dad realized that being retired was actually a blessing. Now he could be with me through all my hospitalizations, giving support, acting as my advocate and watching out for my welfare. A kid can get in real trouble in a hospital without a strong, parental advocate around. For some reason, clinicians rarely listen to a child's complaints. Or worse, how would a child know if the medication being given was the right dosage? Sometimes, it isn't.

Agent Rainey visited us every week on his days off. I liked him a lot since he always made me laugh. I think his jovial demeanor helped keep all of us, except Mom, from the doldrums. Then one day, he was transferred to a federal, law enforcement, interagency training facility to be an instructor. I missed his visits and the funny stuff he said. He called Dad's ICD a "toaster" and once I heard him telling Dad about his "speed bumps," which I later learned meant hemorrhoids. I never understood the analogy of that for a long time.

Rainey liked to drink beer and he never failed to bring several six packs with him when he came to visit, just in case Dad didn't have any on hand. After he had downed several cans, he was capable of saying anything. He joked that since Dad didn't die, he missed getting his "celestial discharge" and he personally had to cancel Dad's appointment with the taxidermist. Both men roared with laughter while Mom just shook her head in disbelief at what she considered crass behavior. She believed that when drunk, a person's true character was exposed, no longer hidden by sobriety.

7. NEW STRUGGLE TO SURVIVE

It's been nine years now that I've been on this earth and Mom, Dad and Tommy were all doing okay. Dad was holding his own with the help of his cardiac meds. His implanted defibrillator now gave his heart those life-saving jolts of

electricity less often than before. Mom controlled her blood sugar level by exercising (walking down and back up our trail), dieting and taking diabetes medications. She no longer required insulin. Tommy made sure none of us forgot to take our pills and scolded Mom whenever she looked at a French cruller. He relished his self-appointed job as the family health cop.

I began experiencing frequent chest pains and felt like spitting up my lungs. My energy level began decreasing dramatically and my body sagged like a water-starved, houseplant. After more tests were done, we all went to consult with Dr. Mutt and Dr. Manos. Both physicians felt that I would benefit greatly if I underwent another operation—a revised Fontan procedure. Mom was against the idea for me to be opened up again. Dad and Tommy only wanted me to get better. After patiently listening to everyone discussing my options, I suddenly chimed in, “Do the operation. I want to feel better!” My nine-year-old assertiveness was the deciding factor. I would undergo yet another open-heart surgery.

Dr. Manos placed his huge hands on my shoulders, his fingers gently squeezing my delicate frame, giving me much needed assurance. I would, once again, trust my life to this caring doctor, who would be carving into my chest with razor-sharp scalpels. I survived three previous heart operations done by this surgeon, so why not one more? Am I not a coffin-dodger par excellence? Have I not squandered all resistance against having another major surgery? The operation took place ten days after the meeting. It proved to be quite difficult.

After being anesthetized and intubated, a venous line was inserted in my upper chest under my left clavicle. The anesthesiologist and Dr. Manos both struggled to get another line into my femoral artery. I was positioned on the surgery table, scrubbed with Betadine and draped.

Dr. Manos reopened my old incision, discarded the scar tissue and removed the sternal wires. He efficiently divided my sternum with an oscillating saw; something that I think has to be the most dramatic part of any chest surgery. With great care, he tediously dissected his way through dense adhesions and tissue to my heart. My old Fontan plumbing was converted to a new, updated one. An electrophysiologist performed an ablation procedure in an attempt to alleviate my annoying, heart flutter problem and a pacemaker was implanted.

Dr. Manos had great difficulty restarting my now unstable heart, but he was not about to give up on me. Finally, my heart began beating weakly and I was disconnected from the bypass machine. Persistent tachycardia episodes further complicated things. My sternum could not be closed until the next day since my

heart was too swollen. It is said that those whom the gods love most, die young. I was hoping that the gods hated me.

Once my chest had been closed and I was back in the Pediatric ICU, I continued having tachycardia episodes and I needed to be cardioverted with an electric shock. My pacemaker's sole function was to prevent my heart from beating too slow and did nothing to prevent rapid beating.

While I was being transferred out of the PICU to the pediatric medical ward, I had a mild stroke, which caused left arm/hand weakness. A CT scan revealed a small area of infarction in my brain's right hemisphere. Now I would be visited by an overzealous, physical therapist twice a day to help me regain strength in my arm with exercise. To this day, two of my fingers don't work well, a reminder of what could have been a much worse event.

There was always something taking place during each passing day, which meant I was getting closer to getting the hell out of the hospital. The first and most significant thing was having that horrible endotracheal tube removed so I could talk and breathe on my own. With that thing stuck down my throat, I couldn't talk, scream or gurgle. With the tube finally pulled out, I could indulge in sucking on spoonfuls of ice chips.

Being a dumb ass, Tommy asked, "Why can't you eat something besides ice?"

"Because I'm eating in," I whispered, pointing at one of my IV lines. My throat felt scratchy when I tried to talk.

"Why do you have two IV's?"

"Because it's illegal to mix medicines together in the same tube," I said, without knowing if it was true or not. I remembered a nurse once telling me that, but she may have lied so I wouldn't have a valid reason to refuse the second IV she needed to stick into me.

Tommy's face twisted when he saw the nurse pull the nasogastric tube from my nose. Rather than hurt, it felt like a really weird pressure sensation, like some miniature vacuum cleaner hose sucking out my sinus juices, er, mucus. I was glad he wasn't around to see my abdominal drain tubes removed or he would probably have puked. I almost did.

Everyone was with me when Dr. Manos came to check on me and pull out my cardiac pacing wires. Thinking it would hurt, I told him that I wanted to do it. He glanced around as if to make sure no nurses were around and said, "Okay, Sara. Go for it." Before he could change his mind, I steadily pulled the two wires

out of my chest. Mom and Tommy were in a state of disbelief. Dad and Dr. Manos looked at each other and smiled. I knew they were proud of me.

In a few days, I would be discharged. I was free to get out of bed and walk around letting Tommy drag my IV pole along. We passed the time playing video games and watching old Laurel and Hardy movies. When we thought no one was looking we snuck out through a red door onto a fire escape platform and sat there on the metal grating six stories up until Dad suddenly showed up. He opened the door, stuck his head out and asked cheerfully, "Do you want to stay out here or go home now?"

8. RUNAWAY HEART

It has been almost two years since my last open-heart surgery and the twentieth century was in its final year. The population of the world, including that speck of humanity named Sara Jones, had surpassed 6 billion. If there was such a notion as a grand scheme of things, then I felt lost in it, like a single grain of sand in an eternal sandstorm. Making matters more difficult for my immature mind to deal with was that Dr. Manos and Dr. Mutt were no longer around. Dr. Manos had relocated to New York and I heard Dr. Mutt went to Hawaii.

Fortunately, Doctor Anastasia Hershe, my new pediatric cardiologist was an amiable lady, who tried to be proactive with my care. Her good-natured demeanor made me like her right away and soon my former doctors faded like shadows into the background of my adolescent memory. She treated me as a little sister and, in time, we grew quite fond of each other. Without her white lab coat on, she looked more like a well-groomed, soap opera actress than a doctor. Mom became upset whenever she looked at Dad with a wispy smile on her face. Dad squirmed nervously, afraid to smile back without invoking spousal jealousy.

Just when I started to believe my body would no longer betray me, it did. For some unexplained reason my heart would start racing, causing me to pass out. Once it happened in radiology while I was in a little closet used for changing into those impractical hospital gowns. I fell down, skinning my elbow and cracking my forehead as it ricocheted off the wall. Twice I think, since I heard two thud sounds before temporarily losing consciousness.

I envisioned what I perceived to be two translucent, winged angels floating above me with confused "what are you doing here?" expressions. One attempted to push at me as if to prevent my spirit from leaving my body. While lying down prone, the blood flowed back into my brain with the help of gravity and I

reopened my eyes, wondering why I was crumpled up on the floor with my head hurting. An irritating, ringing sound echoed within my inner ears.

Dad heard the sound of my body crashing down and got to me before the panicky x-ray technician could shout for help. He lifted me up into a chair as another technician arrived with a look of terror in her eyes. The frightened woman obviously had no idea what to do, so she offered to get me a cup of water. Dad took me to an urgent care clinic in the adjoining building, where a doctor scanned my eyes with a little light, bandaged my elbow and otherwise deemed me okay. Nothing broken, not even my pride.

A drug called procainamide was prescribed to control my speeding heart. It helped lessen the frequency of my racing heart episodes, but it also caused drug induced lupus erythematosus (DLE), an autoimmune disorder that caused my body to attack its own cells. It took several months before the symptoms began to manifest themselves with unusual skin lesions and arthritis. My joints became painful and swollen while my nervous system made me overheat, freeze, itch and writhe in agony. When Dr. Hershe realized what was happening, she immediately took me off the drug. Over time, the symptoms lessened, but would erupt periodically for several more years. I wondered why God had so far spared my life only to see me miserable every day. I did my best not to complain, knowing that no matter how bad I felt there was always someone else much worse off.

Dr. Hershe divided her time between treating kids with congenital heart defects and instructing pediatric medical students. OUCH was a teaching hospital and often, first-year interns would accompany her when she saw me in the cardio clinic. These young doctors, some with arrogant smiles, seemed uncomfortable when we hugged and chatted, sometimes for up to ten minutes, as if our social interaction was foreign to their usual mechanical, learning environment. I was Sara the person, not the “cardiac case” in Exam Room Two. Get used to it.

It always annoyed me during my frequent visits to the cardio clinic when interns queried me about my condition, each one of them asking the same redundant questions. The worst being: “Why are we seeing you today?” I had to wonder if they even read my chart before entering the exam room. I did enjoy watching their bewildered expressions when they listened to my unusual heart sounds and rhythms, knowing they were unlike anything they had heard before. One cocky intern upon touching something unusual under my skin, near my rib cage, asked, “What is this mass?” When I told him he was feeling my pacemaker, his face took on a reddish hue. I think his ego may have shriveled somewhat as well.

Not all of the interns acted like impersonal, white-coated strangers. Some were really cool and I hit it off with them right away. They were the ones who took an interest in me as a person, beyond my medical condition, talking with me about my favorite subject: animals in general and cats in particular. I have never strayed from my belief that people who love animals are inherently good and, conversely, people who mistreat animals are primarily cruel.

When queried about where I lived, I felt sad, since my family now lived in a rented house in the middle of the city not far from OUCH. Medical expenses not covered by insurance had taken their toll and through foreclosure we lost our rural sanctuary. Mom worked as a waitress and did her best to stay cheerful, even though she had left her heart behind in our little, backcountry cabin. Dad managed to bury his despondency into the lowest hollows of his consciousness. Tommy, however, fit right in with city life like a true urbanite. I still had Ninja, my beloved cat, to console me.

I would never get used to living in a metropolitan environment with the air pollution, noise pollution and traffic congestion. No longer could I see stars in the night sky or hear the music of nature. Honking horns and sirens replaced the mournful cry of the coyote, the wind rustling through the trees and the melodies of singing birds. To my mind, the city was tantamount to a living, evil organism made out of concrete, steel and asphalt. The surface streets were like veins and the freeways were like arteries. Cars and trucks flowed like blood cells until a traffic jam clogged the way like a clot, causing an infarction within the city they traversed. It seemed as though the city would someday die from the cancerous blight of congestion and population over-capacitance.

9. TOO MUCH PAIN

Wow. I'm now a novice teenager with six more teen years to go. My story, and possibly my life, could end when I reach that last teen year of nineteen. According to the law of nature, I will be dealing with the dilemma of adolescence, and supposedly, think that I know more than my parents and become rebellious. Trouble is; I'm a little bit of a conundrum, a congenital enigma who doesn't quite fit any modern norm or natural law. If adversity, as Lord Byron suggested, is the first path to truth, I wonder how my health difficulties will enlighten me. And will any enlightenment soothe or irritate my psyche?

Home schooling at the seventh grade level was no longer practical and I enthusiastically began attending a public middle school thinking I would soon

have lots of friends. Once again, my health intervened, screwing everything up. It's hard to get to know your peers if you're sick and absent most of the time. When I did attend school, I wasn't allowed to participate in any physical activities per doctor's orders. I became the weird kid who stayed on the sidelines watching all the other kids play. My only solace was being able to talk with certain teachers or other adults, who understood with some empathy how I felt. Not all did.

During this time my beloved cat, Ninja, passed away from old age. She had been a wonderful pet and I knew her time was almost up because she could hardly stand up. She purred just before taking her last breath to let me know death was fine with her and I shouldn't be grief-stricken. I think my tears flowed more from selfishly missing her than concern about her actual death. Death only brings grief and sorrow to the friends and loved ones who are left behind. I knew Ninja wasn't sad. She was utterly at peace and pain free, yet I still wept for days, feeling sorry for myself for not having her any longer.

On a day before Halloween, Tommy raced into the house shouting, "Sara, Sara. Look what I've got!" He handed me a cardboard box containing a tiny, black kitten. "I heard it meowing. It was on the sidewalk. I almost ran over it with my bike."

My emotions melted on the spot as I gently lifted the kitten out of the box. "You're safe now kitty," I told it. "Don't be afraid. You're my baby now." The kitten looked at me with plaintive eyes and I knew she understood I loved her. I sensed the kitten was a continuation of Ninja's spirit. Maybe yes, maybe no, but we always believe what we want to believe, no matter whether it is actually true or not. She always slept in bed with me and comforted me whenever I was in pain. I named her Luna.

I knew pain. It visited me often. This time a new and different kind of pain began an assault on my abdomen. Dr. Hershe sent me to see a gastroenterologist. At first, I thought he was a specialist who dealt with stomach gas and with his huge tummy he certainly could have been full of it. I hoped he wouldn't fart in the exam room with me in there. The GI physician, Doctor Blue, baffled that he couldn't diagnose my problem began "shot gunning," ordering a vast array of tests hoping one would give him an idea of my problem. The possibility that I was "snowed," which meant I was already on too much mixed medication, wasn't the case either.

Whenever a doctor has no definitive answer about what's wrong, the word *complicated* is used. I was complicated. Often, some doctors would even come up with one other hypothetical factor: My symptoms were all in my head. And so

began my realization that most medical clinicians don't always believe what you tell them. Wait a minute. What's unbelievable about doubling over, grimacing and screaming in agony? Please—give me a break.

An incident that really enraged Dad was when OUCH had no beds available and I was admitted to the main Oakden University Hospital (OUH) instead of going to the children's hospital wing. One night, rather than calling for an on duty resident when I was screaming from abdominal pain, my nurse closed the door to my room so she couldn't hear my cries any longer, effectively ignoring me. Dad became livid when he found out and threatened to tear the hospital down to the ground with his bare hands. From that point on, either Dad or Mom stayed with me constantly during all my future hospitalizations, night and day.

There is a fine line between being a conscientious, assertive patient advocate and being perceived as problematic by the hospital staff. After Dad's tirade, I may well have been thought of as an ass cramp patient by some of the OUH nurses. Excuse me? I thought pain was considered to be a fifth vital sign, causing many other body systems to suffer. Don't patients have the right to be pain free?

Even Dad's complaints to Dr. Hershe went nowhere. Outside of Pediatric Cardiology, she had no influence due to some antiquated, hospital protocol and a lack of communication between departments. The attitude was: we don't tell your department what to do and your department doesn't tell us what to do. That old adage about one rotten apple spoiling the whole barrel can be a two-way street. Justified or not, when Dad launched into his display of anger, his behavior made my family, including me, look horrible in the eyes of the hospital staff. In essence, he became my family's rotten apple, although in a much different manner than the ferret-faced, fat ass, witch nurse who ignored my agony. I love you Dad.

Doctor Blue finally came to check on me during his rounds. Two interns moved along with him as if on invisible leashes. He was horrified to learn what happened and ordered IV pain medication stat. He also ordered another ultrasound to be done and this time my problem did show up. I overheard the ultrasound technician say to the attending nurse, "Tell Blue she's a 'choly.'" Gallstones were now visible and I was scheduled for a laparoscopic cholecystectomy. Don't ask me to pronounce these words. I will never be able to do so.

The difficulty with diagnosing my problem earlier was due to the fact I was so asymptomatic. The first ultrasound technician found nothing significant, nor

did the radiologist who reviewed the tapes, thus giving a very frustrated Dr. Blue nothing at all to go on. That afternoon my inflamed gallbladder was successfully removed and a bed was found for me in Pediatrics.

10. WHY DO YOU SCREAM LIKE THAT?

With the removal of my stone-making gallbladder, that traitorous, diminutive organ that was terrorizing my body, my abdominal pain temporarily ceased. For some unknown reason, which had not been figured out at the time, a new malady had its genesis within me. I developed ascites, a fluid buildup inside my abdominal cavity. None of the commonly known causes for this condition explained why my laparoscopic, gallbladder surgery triggered the problem. Considering the hemodynamics of my body, it was probably only a matter of time anyway.

This progressive accumulation of fluid within my belly became a chronic condition that would require drainage by frequently stabbing a catheter into my lower abdomen, a procedure known as a paracentesis. This would turn out to be an intractable odyssey that would go on for the next six years with an aggregate total of 270 gallons of the straw-colored liquid removed. At first, it would take a few months to accumulate three to four liters of fluid, drained out by what I called a “tap.” In a few years, the time frame between taps would be down to every ten days with up to nine liters of fluid taken out.

Whenever well-meaning women saw me with my protruding stomach, they would politely ask, “When is the baby due?” At first, this bothered me quite a bit and made me even more self-conscious about my appearance. After awhile, I became so used to hearing comments about my pseudo-pregnancy that I just shrugged it off. If I said it was ascites and I wasn’t pregnant, no one would have a clue about what I was talking about. Finally, I just grinned, telling those who asked that I wasn’t pregnant without any explanation at all. This caused a lot of down-turned eyebrows, especially coming from a baby-faced teenager like me. No doubt the consensus was that I must be lying, after all, I couldn’t have swallowed a pumpkin.

In addition to the intermittent pain that always seemed to pop up unexpectedly from my drug-induced lupus symptoms, the buildup of ascites fluid caused tissue stretching and organ compression which brought on new pain. It was equivalent to going through a real, full term pregnancy every ten days, over and over again. Because of this, I resolved to never bear children, which may have

been a great assumption, anyway. Multiple catheter insertions perforated my abdominal wall and, more often than not, scraped or cut a nerve. I was not having any fun dealing with this at all.

My first “tap” took place after going to Oakden’s ER for intense pain. I hated going to the ER. It always meant hours of waiting while the few available nurses triaged everyone. For some reason, pain in and of itself is not considered an emergency. ER nurses and doctors are hardened against all the suffering they have to deal with on their twelve-plus hour shifts. Just like street cops, they have to be or they would become dysfunctional, nut cases. ER people can’t afford to be too empathetic. Unfortunately, when you are in intense pain, waiting seems like forever. If your vital signs are okay, you are most certainly going to sit doubled over in the ER lobby until you develop flat spots on your ass.

Ah, the Oakden ER waiting room, never a dull moment, night or day. Often, the only seats available are next to some transient who goes “code brown” in his pants, polluting the air with stench, almost as bad as the “code yellow” person who dribbles pee onto the floor. There was a time when security people would dump these potential patients out on the street somewhere, but when a few of them died, someone took notice, pointing out that dregs have rights, too.

By the time I was admitted into the ER and laying on the gurney, I let out blood-curdling screams of agony. Changing my body position from sitting and standing to the prone position on the gurney set off sharp, stabbing pains in my abdomen. While I was writhing from my body’s self-torture, the nurse assigned to me asked unsympathetically, “Why do you scream like that?”

Dad was with me and together we simultaneously yelled, “Do something!” If the look in my eyes could kill, there would have been a lot of dead people in the ER at that moment, starting with my nurse.

“I need to get the IV in first and get the doctor’s order for some dilaudid,” she replied, avoiding my stare.

My dad gave her a quick synopsis of my medical history and the nurse seemed to soften a bit. She told the doctor I needed pain medication right away, motivated more to shut me up than because she cared. It would be a long night for all of us, ending when a radiologist punctured my abdomen with a catheter to drain me. Even with lidocaine injected at the puncture site, it hurt like bloody hell. I think my screams woke up the inhabitants in the nearby morgue room.

I hated the potpourri of human misery in the ER: everything from the blood-soaked trauma victim with a face resembling a meat-lovers pizza to the disease-ridden, obese woman in the bed next to mine, who suffered from some

kind of genital thrush. She was a real “double whopper with cheese.” Heart attack patients were never a problem to be around. They were always quiet, in a sort of peaceful state, never moaning or groaning.

Not all of my ER experiences were like taking a walk through Dante’s inferno, though. Sometimes, I was actually able to smile or see someone else smile. I will never forget the little girl who tugged on my jeans to get my attention as I was getting ready to go home. She couldn’t have been more than six years old and for a moment she was all alone, standing next to a drinking fountain. Her arm was in a cast and her eyes sparkled when she looked up at me. “Can you help me get some water, please?” she asked softly. “I can’t reach it.” Her sweet smile was such a contrast to the gloomy expressions of everyone else in the ER. She was a tiny sparkle of light in the midst of an unhappy environment. She made me smile, too.

When my taps began to take place on a regular basis, every ten to fourteen days, it became more practical to have me scheduled for the procedures to be done in the radiology department as an outpatient rather than going to the ER. Eventually, when the procedures became unbearable, they were done with an anesthesiologist in attendance who sent me into a blissful, pain-free sleep. My body had developed a high resistance to all the pain drugs and it was deemed safer to knock me out rather than trying to control the pain with huge amounts of opioids. Dosages that would kill a horse hardly even changed my blood pressure.

11. NPO – NIL PER OS

I celebrated an uneventful birthday in the OUCH Pediatric Wing. Actually, celebrate isn’t the correct descriptive word since there was no party or anything. I was NPO—not allowed to eat anything that day due to upcoming procedures, which meant no cake adorned with fourteen symbolic candles. I suppose the word commemorate would be more appropriate. Mom, Dad and Tommy were at my bedside, singing the Happy Birthday song horribly out of tune. They tried not to sing too loud, not wanting to disturb the skinny, little girl who shared the room with me. She showed she didn’t mind by giggling a lot. I think her name was Tanya. She was twelve years old and had a hole in her heart along with other problems. Dr. Hershe was her cardiologist, too.

I was there to be cardioverted and tested with a different drug for my pain-in-the-ass arrhythmias. I would also undergo a liver biopsy by Dr. Blue and undergo another abdominal tap. A pain specialist had me placed on a PCA pump

to help me sustain a bearable comfort level. All I had to do was push a little, red button and receive the analgesic through my IV line. No matter how frantically I pushed that button, the pump would not allow me to receive a single milliliter more than the prescribed dosage until the correct amount of time had passed. Was I destined to be on pain medications indefinitely? Was I to become an opioid addict, a pain medication junkie, or to put it nicely, chemically dependent? The answer was yep.

Tanya and I hit it off right away. Like me, she was into video games big time and all day long we constantly requested the video game cart to be rolled into our room. She also had a wonderful sense of humor and acted silly most of the time. Constipation was a particular side effect from her medications and stool softeners didn't help much. She hated it when the nurses had to give her enemas, but she never complained. We both snickered when she told me that she had a chocolate hostage inside her 'testines. I felt sad when she left to go home. We both promised to keep in touch. We never did.

In the middle of the night, a new girl was brought in, admitted through the ER for a drug overdose. She was a disheveled mess, shaking hard enough to dislodge clumps of dandruff out of her stringy, blonde-dyed hair. I worried that her IV line would break away even though it was extra heavily taped. I guessed her age at about sixteen or seventeen and I wondered if I would end up like her because of my dependence on pain drugs. I went from morphine to dilaudid to fentanyl. I sucked on those Actiq "lollipops" long enough to break down my teeth, with the bonus of many cavities.

The girl's shaking slowed down and she looked over at me with her big, bug eyes. I imagined those eyes would pop right out of her face at any moment. Blinking must have been a chore. I did feel bad for her, not sorry, just bad. She had a foul, vulgar mouth, complaining about her gang-banger boyfriend, the cops, the doctors and the nurses. It was a litany of "fuck this" and "fuck that." What a bitch.

I was thankful to have Dad staying in the room with me since I was afraid of this she-devil. The Pediatric Ward allowed one parent to stay overnight with their child, providing an uncomfortable, reclining chair to sleep on. Dad pulled the curtain around my bed so I didn't have to look at the screwed-up girl now sharing my room. I buried my head into my pillow to muffle her ugly voice and halfway through the night I finally fell asleep.

The sunlight pouring in through the window woke me up. Dad was already awake. "I'm going to call Mom and check on the car," he said with an affectionate wink.

"Wait!" I pleaded, fearing to be left alone with the she-devil.

Dad pulled back the curtain. The other bed was empty, made up and ready for the next patient. "They took her to the psych ward an hour ago," he explained.

"Can't you stay?" I pouted. Having him around all the time spoiled me.

"Look, I'll be back real soon." He gave me a big hug and started out of the room, then turned. "If they want to do anything—anything at all. Tell them not until I come back."

As soon as Dad walked out and got in the elevator, a phlebotomist came in like a leech to poke me for blood. If I didn't know better, I would have thought that she waited for Dad to leave so she could strike like a coiled viper. I told her to get the blood from my IV. "I can't do that," she said, obviously irritated. "A nurse has to do that and they're busy right now."

"I'm not going to be stuck if I don't have to," I adamantly insisted, folding my arms together.

She had a job to do and my refusing to let her do it meant that she had failed. She took her bruised ego out of the room and promptly found my nurse who really was available. I told my nurse that they were taking my blood labs from my IV line and I had enough needle sticks already. My nurse grinned, said it was fine, and drew the blood from my IV and re-injected it into the blood lady's color-topped vials.

Dad returned thirty minutes later. I told him about how I handled my blood draw situation. He beamed with approval and leaned over to kiss my cheek. I knew he was proud of me, yet again. I also knew, from his breath, that he had just eaten bacon and eggs for breakfast.

"You have a piece of egg stuck between your teeth," I lied. I was jealous that he could eat and I couldn't. I was also angry because my procedures were delayed, making me NPO an extra day. My stomach wasn't just growling, it was howling.

As we talked about my upcoming biopsy, a nurse's assistant rolled the other bed out of the room and brought in a crib from the over-crowded nursery across the hall. My new roommate was infant girl with breathing problems. She reminded me of myself when my medical odyssey began. I smiled at the toddler with affection and whispered, "I understand, little one. I understand."

12. CHAPLAIN

I was sitting up in my hospital bed, gobbling down pancakes and slurping the last drops of milk out of my cereal bowl while watching raindrops splatter and zigzag their way down the window panes. It made me feel like peeing. I also felt like going outside so I could walk aimlessly in the drizzle. Being in the rain always made me feel closer to nature. In a way, it soothed my soul. I loved the way the cool water droplets caressed and cleaned my skin. Sometimes, I became sopping wet, which added to my emotional catharsis.

I had undergone another paracentesis procedure while I was already knocked out for the liver biopsy. I still felt nauseous from the propofol, and the puncture sites from the paracentesis catheter and the biopsy needle were still stinging. I was farting and burping, blowing out from both ends at the same time. My nurse told me it was beneficial and to keep it up. In a hospital there is no need for embarrassment or modesty either, for that matter.

Most of the day was pretty boring. I wasn't in the mood to play any video games nor did I want to see any of the old movies from the pediatric VHS collection. For some reason, maybe a medication side effect or because I couldn't go outside in the rain, I was feeling low-spirited. I had not yet been told what the results were from my liver biopsy. I sensed something was wrong when I noticed the somber expressions on my parent's faces. Even Tommy seemed unusually morose. They had been outside my room talking quietly with Dr. Hershe and Dr. Blue.

"Sara," Dad said. His eyes were moist and misty. "You're going to need a new heart and liver." Mom began sobbing and chanting prayers. Then Tommy began to cry, something I had never seen him do since he was a little one. He was a tough kid.

I fell into a state of disbelief. Crying is like yawning. When others do it, you do too. So my eyes reddened and welled up with my own tears. "What do you mean?" I whimpered.

"Sara, you need a heart and liver transplant. They are going to search for a hospital that can do it," Dad answered with a long sigh.

"No way! I want my own heart, my own liver, not someone else's in me," I wailed. In reality, I had no choice if I wanted to live, which I did.

Doctors Hershe and Blue stood ill-at-ease behind my parents ready to order anti-anxiety medication should I need it and to answer any questions that I might have. I calmed down on my own. It would take a few days before I understood the

enormity of what transplantation surgery entailed. I went from a somewhat confused state of mind to a “holy shit” realization. To fend off depression, I managed not to dwell on it and just live one day at a time. Dad was destined to become the main crutch in my life from this point on. For my part, I would try to rely on the strength of my own spirit.

That evening, when all of our tear ducts had dried out, Mom, Dad, Tommy and I huddled together to make plans. The first and most important thing would be for me to get accepted by a transplant hospital, which meant being medically and psychologically evaluated before a decision would be made on whether or not I would be fortunate enough to be placed on a transplant list. My doctors would set the wheels in motion by making contacts with the few transplant centers that were capable of handling the rarely done, heart-liver combination. Without the transplant, my estimated life expectancy was from one to two years. I would prove the statistics wrong and hang on for five.

I didn't sleep well that night and I knew Dad didn't either since I never heard him snoring. I don't know how he slept in that uncomfortable, recliner chair anyway, even when he didn't have a lot on his mind. Early in the morning a hospital chaplain came to talk with me. Dad decided it would be a good idea if he left me alone with the priest so I wouldn't feel encumbered by his presence. I also knew he had to spend some time sitting on the toilet. Lately, it had become his morning ritual.

The chaplain was an ancient-looking, white-haired guy with a craggy face. He introduced himself as Father McGoon in a really cool, Irish accent. He called me Sara darlin' and told me I was a very beautiful young lady. For some reason, I wasn't flattered at all and thought about kicking him in the nuts if he tried to touch me. When your dad teaches you martial arts it gives you confidence even if you are a fourteen-year-old girl. Jabbing my fingers into the priest's eyes was another option I prepared for.

It was ridiculous for me to be thinking that way since Father McGoon was just a friendly, jovial fellow. His sweet demeanor disarmed my ready-to-fight mode and I quickly felt at ease. I began to like him. His piety and kindness was as genuine as the uncombed mop of hair on his head. I figured Mom had asked him to come and administer to my soul. Come on, Mom, don't you know my soul is the strongest part of me? I love you for caring, though.

“Sara, I talked to your mother,” the chaplain said, making the sign of the cross. “I know you are not religious, but I also know you believe in God and are quite spiritual. Rather than being brought up to follow the beliefs of your parents,

different as they are, you have always been free to think what you want, believe what you want.”

“Religion has too much dogmatism and hypocrisy. You have to blindly conform to everything. You can’t question anything,” I blurted out. “It’s not fair to God and we’re arrogant to think we know what’s best and what’s worse, we do it in God’s name.”

The chaplain seemed surprised to hear me say these things and must have realized I’ve been doing some deep thinking as I attempted to transition into adulthood. He was not angered or disappointed by my words. Rather, he smiled and said, “Oh, my dear. Your mother is right. You do have a very special soul. You are blessed.”

I scoffingly stared into his eyes. “How can I be blessed if I was born with such a bad heart? I should already be dead. It’s the law of nature, you know. Survival of the fittest.”

“The indifference of nature only applies to the physical world, not the spiritual world,” he replied.

That made perfect sense to me. I wondered why I didn’t think of that before. Still, I had to exist in the physical world and, like everybody else, deal with the craziness and unfairness of life. Maybe it would be best to laugh all the way to my grave, at least my spirit would continue on without me.

Before he departed, the chaplain quoted some words from his bible, with me in mind, no doubt. “Behold I have refined thee, but not with silver. I have chosen thee in the furnace of affliction.”

I appreciated the sentiment, although I would prefer being refined with silver.

13. PRE-TRANSPLANT SCREENING

There are only about a dozen medical centers in the United States that have the capability to do simultaneous heart and liver transplants. Ironically, even though OUCH did perform organ transplant surgeries, they were not among them. After some cajoling by my doctors using their personal connections, Mammoth University Medical Center (MUMC) and Pacific Coast Memorial Hospital (PCMH) agreed to evaluate my medical records before deciding whether or not to schedule me for pre-transplant screening. The other hospitals were out-of-state and all turned me down flat. The bottom line was that donor organs were

too scarce to be wasted on a patient like myself, who clinically stood little chance of surviving such an extremely difficult and risky surgery.

MUMC and PCMH were only 30 minutes apart located in the same coastal, metropolitan area of Delta City. Mammoth was a university teaching hospital and Pacific was a renowned private hospital. When both sent letters inviting me for screening, Mom and Dad felt their hopes rise. My own sense of hope was tempered by mixed emotions since I knew I would soon be poked, prodded and scanned like a lab rat. Dr. Hershe suggested I should go to Mammoth, no doubt biased since it was her alma mater.

We lived inland, three hours away if you drove in the middle of the night and five hours away if you drove at any other time. Freeway traffic between Oakden and Delta City was a real pain in the ass and the drive to Mammoth was often difficult for me. My leg muscles would cramp up and I needed to get out of the car and stand up, which meant writhing and wailing like a banshee until Dad, in desperation, found an off-ramp. Trying to pee in a plastic pan wasn't an easy thing to do in the car, either, so I quickly learned not to take my diuretic pills on travel days.

For five continuous days, I underwent test after test, scan after scan, and gave up enough blood to make Dracula drool with envy. First, the cardiac clinicians worked me over, then the liver people, often duplicating the same tests. I was getting tired, angry, and more tired. During the required social worker interview, I stared at the concerned lady through sleep-deprived, contemptuous eyes, which probably would have jeopardized my chances right then and there to get on Mammoth's transplant list, except for the fact she was totally objective, concerned only with how committed I would be in following a difficult, post-transplant regimen.

The physician in charge of my case was a short, stout woman in her fifties who resembled Teddy Roosevelt, right down to the little round spectacles she wore. Dad said she must have changed genders and morphed right off the face of Mt. Rushmore. In spite of being a highly respected director of cardiology, she drew chuckles from the young medical students who followed her around, because she waddled like a duck when she walked. Doctor Florence Nun was her name.

Dr. Nun had me admitted as an inpatient to do more studies and undergo aggressive diuretic therapy before any future decision would be made regarding transplantation. She also scheduled me to have a heart catheterization and be seen by pain specialists. Ugh! I found myself hospitalized once again. This time, I

shared a room with a despondent, middle-aged woman with jaundice. She looked like a half-peeled banana with her hospital gown almost falling off. Please, Dad, quickly pull the curtain between our beds.

What started out to be a one-week visit as a daily outpatient ended with a three-week incarceration at Mammoth, tethered to my bed with IV lines. Oh, those damn IV's, always getting tangled, always crimping, setting off those incessant, beeping alarms, and always hampering your every move. After my diuretic therapy started to take effect, I overflowed my bedpan, prompting an unhappy nurse to expedite my Foley catheter insertion. That code yellow event made me wonder why some doctors choose to specialize in gynecology and have to spend most of their professional lives looking at two bacteria-laden orifices, separated by a "smelly bridge." And, why are there so many more male gynecologists than females?

During my hospital confinement, two more paracentesis procedures were performed and with the intense diuretic therapy, I began to look skinny. The edema swelling had lessened dramatically—for the time being, anyway. After the therapy finished, Doctor Nun ordered a cardiac treatment using an inotropic drug. My heart immediately began to go out of control. Powerful spasms lifted my body off the bed. My chest felt like it was being pounded with a sledgehammer. I shrieked, "Make it stop. Make it stop!" Never had I experienced such a terrifying concentration of fear as if my soul and body were splitting apart in my chest. My frightened nurse reacted fast and closed off the IV a split second before Dad could get to it.

An on-call, resident psychiatrist, Doctor Hyde, came to see me right after the incident. I was still shaking and had the cold sweats. "You gave us quite a scare," he said nonchalantly, flipping through the papers on his clipboard. At first, I wasn't sure if his visit was an attempt to pacify me or to further evaluate my attitude toward transplantation. He told me he needed to write a confidential report, which would go to Doctor Jeckle, the chief psychiatrist and a member of the transplant committee, who would officially interview me in a few days. I knew then that the interview was basically a training exercise for this fledgling doctor to discover any flaws in my character, which would make me unsuitable for transplantation. God help me, I couldn't resist messing with him. I have always loved to watch how people react when I do or say zany things. I believe a good sense of humor helps prevent depression. I often tricked my own mind into believing it.

When queried about having any suicidal tendencies, I told the psychiatrist I had no intention of killing myself, but if I did die for some other reason, I didn't want to be buried or cremated. I preferred to be melted into a liquid so I could simply be flushed down a drain. I suppose that might be considered a little undignified, but it would be environmentally friendly. He leaned over in his chair, scooped up his dropped pen and began furiously writing down the gist of everything I said. I then digressed into a narrative of absurdities.

"You know doctor, I'm like an apple. All shiny outside and all bruised on the inside." He listened, without making eye contact, while scratching out illegible words on his notepaper. When I said a transplant would be like having a worm in an apple, he looked up at me with narrowed eyes.

My dinner tray arrived, providing a welcome break for both of us. The server was a young girl, most likely a new employee, who waited until the first bite filled my mouth before asking with a silly grin, "How's your food?" I couldn't answer without dribbling pureed chicken out over my lower lip. I did manage to mumble something that sounded like "um huhm." Her grin stretched into a toothy smile as she happily replied, "enjoy." She spun around and raced out of the room trying to keep on schedule with her food tray deliveries. Geez, how often have I heard that redundant word "enjoy" while dining in restaurants? It didn't seem to fit in a hospital setting at all.

14. PSYCHIATRIC EVALUATION

I have heard people say that psychiatrists are often more looney than the patients they treat and you need to be somewhat mentally off-kilter in order to study sick minds. I would never presume to know if this was true or not. I do believe that minds are like fingerprints, where no two are alike. I also think a fine line exists between high intelligence and lunacy. I was glad to be deemed mentally average, far away from any such line. I wondered if that fact would help my case to become a transplant candidate.

A nurse had come over from the psychiatric wing of Mammoth, more esoterically known as the "Vegetable Garden," to transport me in a wheelchair to my pre-transplant, psychiatric interview with the esteemed Curly Jeckle, MD. The corridor we passed through was eerily empty of people. The doors to all the rooms were closed and locked. Security screens covered opaque windows. The polished floor was shiny as glass, reflecting our images as we passed. It seemed as if we were floating down the waters of a subterranean canal. From behind the

doors came sounds of moaning, sobbing and an occasional muffled cry. I felt afraid and was glad to have Dad with me.

We entered a lobby decorated with glossy, plastic plants through a side door marked, "Employees Only," passed a reception desk next to a large, saltwater fish aquarium, and went straight into the office of Dr. Jeckle. He welcomed me with a big smile plastered on his face and had me exchange my wheelchair for a comfortable recliner. Dad waited outside in the lobby, watching the fish dart around and reading year old magazines. I studied the psychiatrist as much as he studied me. I gazed at his baldhead and thought it funny that his first name was Curly. His head was shaped kind of strange, sort of bulbous in the back and just as shiny as the corridor floor.

"You're quite a pretty girl, Sara," he said in a friendly tone. "And smart, too, I understand."

"Thank you. Flattery will get you nowhere," I said facetiously. He laughed and I felt more at ease.

"Okay, here's the deal. I already went over your medical records, the social worker's report and read Dr. Hyde's report. I don't think I need to put you through a frivolous question and answer routine. What do you think?"

I couldn't believe it. This guy was being really cool. The answer tumbled from my mouth without any thought behind it. "You mean like asking if I know what day, month and year it is? I think that would be silly, anyway," I said. I knew it was September 2003, but lost track of the day.

"What would you like to talk about? Pick a subject," he suggested. "Your health, for example?"

"No, not that!" I said emphatically. Even though Dr. Jeckle was being friendly and making conversation easy, which I appreciated, I quickly realized that I was under the magnifying glass. My words and my body language would be scrutinized to see if I had any maladaptive or compulsive behavior patterns. Whenever he carefully coached or attempted to lead me into talking about a particular subject, such as my medical condition, I turned the path of the conversation in a new direction. We played a sort of clandestine chess game between our two minds, complete with all the collateral psycho babbling.

When he started fishing around, trying to learn how I behaved socially, I stayed on course and told him about the fun I had at a theater, makeup artist class. My age prevented me from actually enrolling in the evening college course, prompting Dad to enroll. This enabled me to go with him, after obtaining the

instructor's permission, as an audit student not to receive credit. Soon, my 15-year-old, enthusiastic attitude turned me into a sort of class pet.

I maintained eye contact with Dr. Jeckle while telling him about the time all the students were assigned to make each other look like their opposite sex. The men had to appear as women and vice versa. Seeing all the ladies transformed into men was funny, but seeing all the guys after they were made up to look like women was hilarious. Dad walked around the classroom, smacking his newly made up, bright red lips, tousling his blonde wig with a limp-wristed hand and swaying his ass like a seductive vamp. I went alongside him wearing a man's overalls, a fedora and face shadow to emulate a beard.

At the end of class, all the students went to the sinks to clean off all the makeup from their faces. Often, it was difficult and time consuming to get it all off. Dad and I decided to go home and clean up there. Mom called on the cell phone and asked us to stop at the market for toilet paper since we were all out of it and we certainly couldn't do without something like that. Dad pulled the car into the market parking lot and we hopped out still in drag.

Inside the market, people stopped in their tracks and stared at us in disbelief. Some mouths dropped while others displayed stupid-looking grins. Shopping carts banged together as customers gave us a wide berth. We found ourselves alone in the checkout lane, carrying our sole purchase, a 24 pack of extra-soft toilet paper. The cashier seemed nervous until my dad whispered to her, "We're just actors in costume." Enlightened, she smiled brightly and winked at us. At that moment, she became the only one in the store who knew we were not what we appeared to be.

Dr. Jeckle seemed genuinely amused by my little tale. "I imagine the age difference between you and your dad made everyone react even more uneasily."

"Doctor Jeckle, may I ask you something?" I was concerned about the way doctors and nurses wrote down their observations, which became part of the permanent medical record.

"Certainly. What is it?"

"If I do something, like refuse a water pill, and the nurse writes down in my chart, 'refused,' it looks like I'm being a bad patient to whoever reads it later, because the reason isn't put down."

"Why wouldn't you take your medication?" he asked.

"See? If the reason were written down, you wouldn't have to ask. The implication will always be a negative one, like 'uncooperative patient.'" I explained that being unable to pee during a several hour jaunt on the freeway

with no access to a bathroom was reason enough to skip taking the diuretic, hence my refusal to do so.

This train of thought led me to mention how reports written by certain doctors seemed to imply that whenever a problem existed, the patient was the cause and never the doctor. Not that I didn't think it necessary for doctors to try and cover their asses with all the frivolous law suits being filed, but a little more honesty would be nice.

"What makes you think that?" Doctor Jeckle asked.

"I read my medical records," I answered. I couldn't wait to read his report about me when it became available from the hospital records department.

He paused for a second and spoke again. "Sara, it has been really nice talking with you, a real pleasure, indeed. Here, let me help you back into your wheelchair."

I thanked him and listened while he explained how important family support would be if I were to receive a new heart and liver. "You can't get any better support than what my family gives," I said with great conviction.

"Of that I have no doubt, whatsoever," he said, pushing the intercom button for the nurse to come.

15. PAIN MANAGEMENT

Although, Dr. Jeckle didn't mention it, my reliance on opiate pain medications would need to be resolved before I would be considered for placement on Mammoth's transplant list. The interaction between post transplant medications and pain drugs could be difficult to manage, along with the accompanying side effects that might screw up the recovery of my emaciated body. Since my nervous system had already built up a super high tolerance level to pain drugs, even higher dosages than normal would be required after transplant surgery, which could drop my blood pressure and cause respiratory problems. Not a pleasant outlook, but still better than bellowing in agony as far as I was concerned.

Doctor Alice Feelgood, my new pain physician, didn't think my pain issues should have anything to do with the decision on whether or not I should be placed on the transplant list. Doctor Nun emphatically disagreed. She considered her colleague an over-educated theorist, who spent more time obtaining degrees than gaining experience from personally treating patients. I liked Doctor Feelgood a whole lot and she became my favorite doctor at Mammoth, on par with Dr.

Hershe at OUCH. She was empathetic and grandmotherly with me and I loved it. Her white hair, pulled back tightly into a ponytail, made her look fifteen years younger than her actual 70 years.

I developed spontaneous bacterial peritonitis (SBP) a day before my scheduled discharge. This inflammation of the peritoneum caused a new source of abdominal pain and I had to stay hospitalized for five more days on powerful IV antibiotics. During this extra time in the hospital, Doctor Feelgood saw me every day. She took a special interest in my care, either because I presented a medical challenge that piqued her interest or because she took a liking to me. I hoped it was both. Mom and Dad were grateful for the extra attention she gave me, not wanting me to start having a pharmaceutically enhanced personality, that is, to be stoned on drugs.

At last, I was going to be set free and go home. I sat on my bed, dressed, disconnected from my IV line, waiting for my nurse to bring me my discharge instructions and prescriptions. I couldn't wait to be home and hold my beautiful kitty, Luna. I glanced over at my latest roommate, who lay comatose on her bed. Her ashen face had an aura of death about it. I felt terrible for her, although I sensed she had endured enough suffering and welcomed an imminent demise to set her spirit free. Death would certainly be a remedy for all her ills. She was a "cut and paste," opened up in surgery only to find she had no hope and sewed back up again. I touched her hand for a moment before leaving. I never did inquire about her illness, although the nurses would never directly discuss something like that with a non-family member. It wasn't any of my business, anyway.

Dad took me to see Doctor Feelgood at her pediatric pain clinic twice a week. The clinic was located in a satellite building on the Mammoth campus, free from all the hustling crowds and chaos of the main hospital building. On some days, I had appointments at both locations. The pain clinic was like a small fiefdom and Doctor Feelgood was the benevolent lord and master, overseeing an ensemble of dedicated specialists. Her staff included: two pediatricians, an acupuncturist, a hypnotherapist, a massage technician, an art instructor, two physical therapists, and a musician.

Doctor Feelgood personally managed my medications and my neurological studies, while the clinicians did just about everything else. Since I didn't respond well to acupuncture, that treatment was cancelled. I laughed when the acupuncturist parted my hair and stuck a needle right on top of my head. It seemed so ludicrous that I couldn't help myself. I think I ruined her day with my

sudden outbreak of merriment when I should have been serious and compliant. I meant no disrespect.

One by one, all the other treatment protocols failed to relieve my pain, as well. The hypnotherapist didn't put me to sleep like I expected. Rather, the sessions with her were meditation training. I tried to erase all the jumble of thoughts in my mind and focus on only one single thought. I attempted to concentrate visually on a single object—a burning candle. It went out, leaving a wispy trail of smoke hanging in the air. My mind returned to a flurry of thoughts and imagery. I needed outside stimuli to function, like the sounds of talking and music or seeing the action of life around me. Quietness and solitude only brought disharmony and sleepless nights. Insomnia was a familiar acquaintance of mine.

I responded well to art and music therapy, since I am a right-brained individual. When I sketched and painted pictures, I was focused and in harmony with my thoughts. I felt better, but creating art cannot be done 24 hours a day, seven days a week. Listening to music and, sometimes singing, was something I could do, almost all of the time. At home or in the car, I constantly listened to music: rock, country, classical and more. I also loved seeing movies in all the genres.

I never saw a physical therapist at the pain clinic. I had told Doctor Feelgood about my past experiences with overzealous PT's and how they had caused me more harm than good. They pushed me too hard and fast concentrating on my muscles and joints without regard to my sick organs.

Dr. Feelgood put me on those fentanyl "lollipops" and sucking on them along with saturating my mind with music gave me a fairly pain free life for awhile. Unfortunately, having those berry-flavored things stuck in my mouth brought about a whole lot of cavities. To save my teeth from less destruction, I was switched to fentanyl buccal tablets. They worked faster, but were not as long lasting. It was hard, sometimes, not to take one too often or too soon. These opiate drugs helped hold back the achy, chronic pain I felt in my arms, legs and abdomen, but only took the edge off the sharp, stabbing, acute pain attacks. Rather than moving away from drug addiction, I was becoming even more dependent on them. Over time, I became friends in succession with morphine, demerol, dilaudid and fentanyl. Not at the same time, however. I was pain incarnate.

Doctor Feelgood told me not to worry about chemical dependency. She never used the word addiction. "In time, things will get better," she said. Yeah,

right—provided I get transplanted, my ascites stops or I cease to exist, whichever comes first.

16. DENTOPHOBIA

As a heart/liver transplant candidate, I needed to be free from any potential dental problems that could cause an infection. This was particularly crucial and essential for a newly transplanted heart. A dental evaluation and treatment needed to be accomplished expediently, with the extraction of any compromised teeth preferred over repair. If anyone badly needed dental work, I certainly did. Nothing worked out, as it should have.

My dentophobia was as bad as it gets, which didn't help matters. I would do anything to avoid sitting in a dentist's torture chair. Only when a toothache became unbearable, would I reluctantly open my mouth, allowing that terrifying, whirring drill to grind away at my teeth. It was absolutely necessary for me to always have Dad present so I could grasp onto three of his fingers in a death grip. I couldn't hold more than three fingers with my small hand and if it were less than three, I think I would have snapped them like a twigs from raw adrenalin power.

A few years before all this transplant stuff started, I needed to have a few cavities filled and a not-so-gentle dentist didn't use enough novacaine. "Just a little pinch," he lied, poking his syringe into my hypersensitive gum. Then he sadistically let the drill pressure go on for too long. The friction heated up my tooth and I ended up thrashing in pain, tears flowing down my cheeks. That was the last and only time I have been alone with a dentist. I wished Dad could have been there then to bust the dentist's sullen mouth with his fist. I like to think he would have done so, on my behalf.

Succumbing to Dad's persistent persuasion, I relented to undergo a general dental exam to find out what treatment I needed. For this, I knew the hardest part only amounted to having those little, cardboard holders for the x-ray films jammed into my gums. I could withstand that. When our family dentist learned I was in need of a heart and liver transplant, he refused to examine me. The same thing happened again with another dentist, who suggested I go to the hospital dentistry department at Mammoth. I couldn't believe it. I had to return there even for dental work.

After reading magazines with torn out pages and picking my nose for three hours in the waiting room, a young Korean dentist finally saw me. Her eyes darted back and forth between my gaping mouth and my x-ray films, while scratching my

teeth, one by one, with a stainless steel pick that she clutched in her well-manicured talons. She behaved like an excited vulture working over a hunk of carrion—me. An even younger dental assistant dutifully wrote into a chart everything she said.

“Miss Jones, you need lots of work. How did your teeth get so bad?” she asked with an irritated tone. I explained how fentanyl lollipops were famous for causing decay. She had never heard of them. And, I confessed that I was a candy loving, not-so-often brusher to boot.

The dentist glanced at me, then at Dad, and rattled off a list of the treatment I would need, one tooth at a time, in order to be cleared for transplantation. Once I realized that half of my teeth should be extracted, I stiffened with apprehension. On the surface, my teeth were still white enough to allow me to flash my trademark, million-dollar smile. Sure, I could have cosmetic dental work done later, but that meant I still had to deal with my greatest phobia. Otherwise, I would be condemned to have a smile akin to that of a hyena. I thought about how horrible that would be, avoiding eye contact with the dentist.

The solution seemed simple enough, have my dental work done while sedated under general anesthesia. If I’m asleep, and unaware, I could handle anything. I wondered if sleep was a form of bravery. Then to my surprise, I was informed that the dental anesthesiology specialist at Mammoth wouldn’t help me due to what he considered too great a risk. I was flabbergasted. Mom and Dad were dumbfounded. Tommy was ticked off, considering it an act of cowardice. When Doctor Nun was asked to intercede on my behalf and talk to the anesthesiologist, she declined, saying she couldn’t take the responsibility. Huh?

In desperation, Dad located an oral surgeon who agreed to sedate me because of my dentophobia. He was not told anything about my medical history. My four worst molars were yanked out without any problem. Dad made sure I took antibiotics before and after the extractions. Other than a little swelling and a lot of soreness, I tolerated the procedure well. With those problematic teeth gone, the chance of my developing an infection lessened dramatically.

A few weeks later, I returned to the same dental practice where my oral surgery was done to have the rest of my dental work completed. Even though I knew I would be sedated, I leaned back in the dentist chair still sweating with fear. I worried that the dentist would notice my heart pounding from nervousness. He didn’t and since I was supposedly in good health, no one took my pulse, at least not while I was awake to notice. The beads of sweat on my

forehead were noticeable, but that only confirmed my phobia and the justification to sedate me.

I suppose some people will say it was wrong for me to undergo dental treatment without informing the dentist about my medical condition. On the other hand, was it wrong for my family and I to do whatever it took to try and keep me in the land of the living? No way was I going to be excluded from a transplant list just because certain dentists were refusing to treat me under anesthesia. Omitting facts wasn't as bad as direct lying and since the treating dentists had no knowledge of my condition they bore no responsibility had anything gone wrong.

I was given a "to whom it may concern" letter as evidence that my teeth and gums were without problems. Even if the treating dentists found out later about my actual health status, it wouldn't take away the fact that my teeth were no longer precluding me from transplantation. As far as I know, these dentists never learned of my true medical condition.

Two of my extracted molars did cause noticeable gaps in my upper teeth. This spacing didn't ruin my smile in any way and in time closed in until I had no need for any cosmetic work after all. I was happy my smile didn't resemble that of a hyena.

17. 5-H-I-T

I was approaching my fifteenth birthday, Christmas time and the end of 2003. It was raining so I was happy. My kitty, Luna, watched me through the kitchen window walking around in the backyard, no doubt curious as to why I liked getting wet. Getting water on her silky, black fur was quite an abomination, which made her think I must be crazy as a drooling-mouthed dog. Tommy thought my getting wet for no reason was stupid. Mom worried about my catching a cold and Dad enjoyed my happiness with his usual understanding.

I came into the house, changed into dry clothes and began playing a video game with Tommy. We were overzealous video gamers and wasted away many hours pushing controller buttons. It was another way for me to take my mind off the intermittent pain pulsing around my body. Luna, ignored my game playing and cuddled up next to me on the couch, happy I came in out of the rain. Dad watched us play for a while then went to answer the doorbell. It was the mailman needing a signature for a registered letter.

The letter was from Mammoth. We all looked at each other, hoping it would be the good news informing me I was on their transplant list. Dad began

reading the letter out loud. His voice fell silent and he looked at me with eyes full of sadness and disbelief. Tears began trickling down Mom's face. I knew then that the news was bad. I would not be on the transplant list. I pulled the letter out of Dad's hands and read it to myself.

*MUMC Transplant Selection
Committee Meeting - New Evaluations
December 04, 2003
Sara Jones - MR# 00110-666*

The MUMC Transplant Selection Committee met and this patient's heart and liver transplantation candidacy was discussed in detail.

This patient is a 14-year-old female with congenital cardiomyopathy and Fontan physiology. She has undergone 4 prior cardiac surgeries and now has NYHA functional class III heart failure.

The patient has the following additional medical problems: her major problem clinically is hepatic cirrhosis with recurrent ascites requiring frequent paracenteses. She underwent an attempt at Fenestration enlargement but she has not had sustained improvement from this. She has tremendous difficulty with pain management and procedure related anxiety. She has very high pre-formed antibody levels.

After careful review and comprehensive attempts at medical and psychiatric interventions, the decision of the transplant selection committee is that Ms. Jones is an unacceptably high risk candidate for transplantation due to her multiple prior thoracotomies in conjunction with her hepatic dysfunction, high preformed antibody levels and her pain control and anxiety issues.

Dictated by: Florence Nun, MD

5-H-I-T is medical slang for shit and that's what I felt like. Almost seven months had been trifled away at Mammoth. Time was eroding my chance to stay alive. One thing was certain. Dad was not going to stop doing everything he could for me. He would never give up hope and if he wouldn't than neither would I, no matter what. He made calls, wrote letters and sent e-mails to newspapers and

television stations on my behalf. Soon, my story came under the media radar. Reporters from one of the local TV stations and the Oakden Chronicle interviewed me.

The newspaper reporter and photographer were fairly easy to deal with, but talking in front of a TV video camera took some getting used to. The TV people were happy with me since I was a young, innocent girl in trouble, needing help, who happened to be photogenic and talked in sound bytes. In reality, underneath my charismatic façade, I wanted to flee, to escape that inhuman, camera lens that seemed to peer into my soul. I couldn't escape with Luna resting on my lap, purring away. Besides, I was too frozen to move.

I wondered how the interviews would turn out. Would the newspaper print some personal or silly thing that I wished I hadn't said or take some of my words out of context? From all the photos that were taken, would they use one that showed my ascites swollen belly? Oh God, I hoped not. The television story was to air on the same day as my interview during the evening news. How would they edit a half hour interview down to a minute and a half? Would I come across looking like an unwed, pregnant teeny bopper?

I didn't mind the questions related to my health and the important need for organ donation. I hoped they wouldn't report on my problems with school, such as my being unable to complete classes from lack of attendance. I have never been pleased about that. Although, I have always been proud of Tommy's academic accomplishments, I still couldn't help but feel envious. He was an honor student in his last year of high school and I was just a part-time, special education student with no foreseeable future, unless I could beat the odds and receive a new heart and liver before it was too late. The newspaper article and the TV story turned out amazingly well done, much to my relief.

The Oakden Chronicle ran my story on the front page with a picture of me holding Luna. It appeared, by extreme coincidence, on my birthday. The title read, "Sara Jones: Fighting for Survival." It's funny how others perceive us differently than we see ourselves. I never thought I was anything like the way the writer described me. A fighter? I don't think so, not me. Courageous? Whoa, Dad is, not me. I'm a big chicken. Sweet? I guess I can be if I try, but it's easier to be the opposite. Hopeful? As long as Dad says there is hope, I won't give up on that. I have no intention to meet up with the grim reaper. He's a real asshole.

Seeing myself on a TV news broadcast was weird. I didn't think I looked like that. For some reason, the camera liked me and made me look better than I really am in person. Luna looked so cute in my lap and helped to hide my bulging

tummy. My voice sounded strange to my own ears, like when you hear yourself played back on a tape recorder. When the reporter asked what I wanted to do with my life if I received a new heart and liver, I shyly answered, “Go to school and study zoology.”

No one could hear my spirit saying, “To soar like an eagle on the winds of destiny.”

18. GUARDIAN ANGEL

The newspaper story about my fight to survive caught the attention of a philanthropist who wanted to personally take me on a trip to Disney World. At first, I couldn't believe it, but it was true. Doctor Hershe said it would be okay for me to go as long as I didn't forget to take my medications, an easy thing to do when having fun, although pain attacks would always serve as an effective reminder. Before I could travel, my ascites fluid had to be drained and again upon my return home two weeks later. My entire life revolved around paracentesis procedures and I hated it.

I watched the silver, G4 jet aircraft slide out of the early morning sky, landing smoothly on the main runway at Oakden International Airport. It taxied across the tarmac and came to a halt in front of the private aircraft terminal where I waited anxiously with Dad and Tommy to meet the sponsor of my Disney World trip. All of us would be going together with the exception of Mom who preferred to remain at home with Luna and enjoy some peaceful solitude.

A few days earlier, Dad received the itinerary and details for the trip, along with two specific requests: that my sponsor would be anonymous to everyone outside of my immediate family and that I be treated like a princess. I could hardly contain the excitement welling up inside me. We were to fly across the country to Florida in a private jet, stay in a luxury suite at Disney World for three days, while a Disney representative escorted us wherever “princess me” desired to go. On the third day, my sponsor would leave us and fly back to the West Coast. Arrangements were made for an SUV to be available so Dad could take Tommy and I down to the Keys where I would swim with dolphins. Then we would drive cross-country, sightseeing all the way home.

While streaking across four time zones at 500 miles per hour and 50,000 feet above sea level, I became acquainted with my sponsor. She had an angelic smile and sepia eyes that sparkled with fervor. On the flight, we hit it off, enjoying each other's company immensely. In spite of the 25 years of age separating us, she eventually became, in essence, like a big sister to me. In some unexplainable

way we shared a spiritual connection. She would become my guardian angel and friend, affecting my outlook on how I perceived life, restoring my faith in humanity. Her name was Jane Doe. How's that for an overly used pseudonym? It seemed like I was in a fairy tale complete with a fairy godmother.

I looked out the G4's window at the clouds scurrying past below and pretended we were all on a magic carpet. Jane's personal assistant, a pretty, pony-tailed blonde named Susie, recorded my joy with a digital camera, which would be given to me upon landing. The flight attendant strapped me into a jump seat behind the pilot, which gave me a cockpit view as we banked into the final approach to the airport. My heart raced, almost going into fibrillation trying to keep up with the speed of the aircraft, until we safely touched down on terra firma.

On the ground, a long, black limousine moved up next to the G4 to pick us up. Dad and Tommy didn't know what to make of all the special attention. Jane and Susie stuck with me like glue, staying by my side, arm in arm, tending to my every whim. Of course, I loved being spoiled rotten, even if only for a few days. I smiled so often my cheeks began to ache. Living a life of luxury is definitely something I could get used to real fast.

Dad and Tommy entered the limousine first so I could be nearer to the door. It would have been difficult for me to make my way to the furthest seat with my edema-swollen legs. What is so special about being in a stretch limo if you have to crawl like an iguana to reach your seat? I think I figured it out. It's the bar. How else can you legally drink in a motor vehicle? I noticed that everyone, except me, was feeling a little tipsy from all the wine consumed on the plane. I decided it wasn't fair for me to be denied alcoholic beverages simply because I was sick and underage. While everyone chatted like drunken sailors, I surreptitiously sampled Jane's Pina Colada at every opportunity. I'm sure she was aware of my covert drinking since her glass emptied sooner than it should have. Dad noticed my stealing sips from her glass and pretended he didn't see me. What a great old man I had for a father!

The hotel suite reserved for me had more floor space than my home. This luxurious accommodation would have impressed a Russian Czar. I had no idea that suites like this even existed other than at the palaces of kings. I loved, most of all, soaking in the over-sized, whirlpool bath, dreaming of meeting a handsome Prince Charming. Even though Dad and Tommy were relegated to stay in the connected servant's quarters, they were quite satisfied with its epicurean

ambiance, not to mention a double-door refrigerator well stocked with bottles of beer.

During dinner that evening, I met Dave, our Disney World representative who would be with us during our daily excursions around the park. He was the first openly gay person I had ever met, a wonderful human being, dedicated to his job and so damn funny. He made all of us laugh constantly. Much to my delight, I enjoyed a few glasses of red wine, with the permission of Dad and Jane. Even Tommy felt like an adult, sipping on a beer in full view of the whole world. Somehow, I knew no one was going to question our ages even though we were obviously under 21. It felt cool to be immune from prosecution, safe from the local gendarmes. Before dinner ended, I began to feel warm and fuzzy, but without knowing what really being plastered actually felt like. The first day of my trip turned out to be extraordinary wonderful. That night, tangled in my blankets, I wept tears of joy and fell into a deep sleep, insomnia free.

19. DISNEY WORLD AND AFTER

My three days exploring Disney World ended all too soon. On the last day, Jane, Susie and I behaved like over-enthusiastic Valkyries on a climaxing binge in Valhalla. Dad and Dave chased us around like a couple of sulking security agents, protecting us more from ourselves than anything else. Tommy took off on his own to go on those fast moving, roller coaster type rides that I couldn't handle without puking my guts out. Although asymptomatic for inebriation unlike my two female partners, I made up for it by being drunk with giddiness.

We resembled shit-faced vagabonds with our tousled hair, beverage-stained shirts and rumped down socks. I had on a pair of baggy shorts since my legs were too swollen to wear pants. The shorts looked like two shopping bags sewn together with my legs hanging out like flesh-colored cucumbers. Jane and Susie both wore faded jeans with holes in the knees, which ripped open further whenever they climbed in and out of the rides. To us, casual was just another word for messy.

Jane's tawny hair floated past her shoulders, partly obscuring the words "Mind Your Own Business" silk-screened across the front of her t-shirt. Susie wore a more conservative, less stained shirt with "CIA" emblazoned in large letters across the front. Her boobs added an extra, three-dimensional effect to the letters. I dutifully conformed to the theme of Disney World by wearing a Lion King shirt and a Mickey Mouse cap with large floppy ears.

Susie began to hum and then burst out singing, "Sail on silver girl, sail on." Jane and I joined in, hopelessly off key. "...your time has come." From among the throngs of people around us came stares of disbelief. No one in the crowds at the "happiest place on earth" seemed happy at all with our ragamuffin behavior. They were not impressed in the least by our voices. Unperturbed, we continued, "I am a rock, I am an island."

By the time we made it to the Pirates of the Caribbean ride, the boys caught the mood, joining our songfest. "Yo, ho, ho and a bottle of rum," we all sang into the darkness as our boat slowly slipped along through the murky water. Blackbeard would have been proud. Aaargh!

After the ride, I became subdued and pensive, realizing the day and our time together were almost over. That night, as I watched fireworks explode in patterns of color across the sky, I talked with Jane about trifling things, not wanting to dwell on her leaving in the morning. I brought up whatever popped into my head: my first sip of wine, the rides, the giraffes hiding behind a Baobab tree and the strange way people glanced at us. She knew parting would be tearful for me and promised we would get together again real soon. Like a true friend, she would keep her word. I could not have imagined where.

As the G4 flew westward, Dad drove Tommy and I toward the Keys. The funk I was in vanished when we arrived at the cetacean research facility where I would meet and swim with bottlenose dolphins. I have always been fascinated by these intelligent creatures and felt a strong affinity with them. The dolphins were separated by pairs in holding ponds connected to a canal that emptied into the Atlantic on one side and the Gulf of Mexico on the other.

Before I went in the water with the dolphins, a trainer taught me how to interact with them from the dock, giving hand signals and tossing mackerel into their mouths. I didn't like handling those smelly fish very much, but if that helped make me their friend, I was all for it.

Due to my health status, the trainer needed to go in the water with me. We swam out to the center of the holding pond and treaded water five feet apart. If I needed to be saved from drowning, I wondered who would rescue me first, the trainer or one of the dolphins? I noticed one of the dolphins was half the size of the other and I realized, much to my delight, I was with a mother and her offspring. The calf spent a lot of time studying how its Mom behaved with me, spinning alongside while Mom towed me around the pond as I hung on to her dorsal fin. My grip weakened and I let go. The trainer immediately swam up to me

and checked the life vest that kept me from going under. I swallowed a little bit of seawater and almost choked, but I was happy as a mermaid.

The most amazing thing was how the mother dolphin swam around me, pausing several times, while I treaded water. She examined me with her echo pulses, peering through my body similar to an echocardiogram. I sensed that she knew my heart and liver were defective. She gently nudged my upper abdomen right where my pacemaker was located and, as a final gesture, put her rubbery nose against my cheek. I affectionately kissed her and she made a series of clicking sounds as she sank backwards toward her calf. No other animal encounter is etched more deeply in my memory.

The next day we began our road trip home 2,800 miles away. First we stopped at an alligator farm so I could see those super-sized reptiles up close and personal. Tommy talked me into trying some gator nuggets for lunch, which I imagined was how shit tasted like. A few bites and I felt like throwing up. It didn't help when I found out it really was made from the meat of an alligator's tail. Damn you, Tommy!

The reptile show featured a guy interacting with a big gator and displaying a variety of snakes, including a non-indigenous boa. He reminded me how some people resemble the pets they own, especially when it came to dogs. He was tall, thin and moved as if he were an undulating wave. Even his head seemed alien and snake-like, lacking only a forked tongue. When he lifted the nine-foot boa off his shoulders and asked the audience if anyone would like to hold the serpent, I raised my hand and jumped up. "Me!" I yelled, before someone else could beat me to the opportunity. The boa curled itself around my torso while I held its head up high enough for Dad and Tommy to see. They worried the snake might crush the air out of my lungs. After all, it was a constrictor.

Since I had to be home in time for my next scheduled paracentesis procedure, we sped across the Southern half of the country, spending little time sight seeing. The Grand Canyon was the exception. I was spellbound, standing on the rim, looking out across this geological wonder of nature. I could not fathom why people had so little respect for a planet as beautiful as ours. Since we are all a part of the earth, does it mean we don't respect ourselves?

20. SPECIAL PROCEDURES UNIT

My paracentesis procedures no longer had to be done in the ER or on the pediatric floor. Even better, a standing order was written requiring an

anesthesiologist to put me under during my taps. I suppose no one wanted to hear my blood-curdling screams every time that damn catheter was pushed into my abdomen. It felt like a knife stabbing me.

I went, with a belly full of fluid, to the Oakden University Hospital's Special Procedure Unit for prepping and recovery monitoring. From there they wheeled my gurney into the ultrasound room where a radiologist, guided by an ultrasound image, punctured my flank with a catheter that emptied into as many one-liter, vacuum bottles as it took—eight liters on average. Propofol, or milk of amnesia as the nurses called it, kept me in dreamland until I woke back up in the SPU. I received IV albumin and pain meds, until Dad took me back home several hours later.

The SPU nurses were used to seeing older, adult patients, who were there for one day, outpatient procedures: angiograms, ICD implants, cardioversions, transesophageal echocardiograms and so on. Since I was only sixteen, in need of a heart and liver transplant and I came so often, the nurses developed a special interest in me. They spoiled and doted on me as if I were a celebrity VIP. Naturally I loved all the attention, lapping it all up like a dog at a gravy bowl. For six particular nurses, it was a mutual admiration relationship and over time we came to love each other like family.

Wendy, the charge nurse, was a 20-year veteran and the efficient boss of the SPU. She stood six feet tall and reminded me of Wonder Woman with blonde hair. Due to her extensive medical knowledge and political savvy, she commanded the respect of the entire hospital's medical staff. With her watching out for my welfare, Dad never had to worry about my care. Even though he felt at ease leaving me in the unit, he preferred to stay so he could talk with the nurses at every opportunity. Like me, he received plenty of hugs. He became the consummate old fart.

Nurses Eileen and Carrie looked and behaved like female versions of Laurel and Hardy. So much so, it made reincarnation seem like a possibility. All they needed were bowler hats to complete the picture.

Ana was a hot looking Latina, who set off Mom's jealous nature by swinging her foxy ass whenever she passed by Dad. She was definitely eye candy. Then during one visit, Mom saw her walking hand in hand with a female x-ray technician and her jealousy quickly evaporated.

Rachel was a talking machine who never shut-up. Her voice was soft as a cat's purr so no one minded her motor mouthing. Her peers simply tuned her out, not paying any attention to her frivolous rambling and she never seemed to be

bothered by it. I surmised that she must have grown up talking to a wall. On the rare occasions when she did raise her voice everyone paid attention for that meant she had something serious or important to say.

Dear Emma, my favorite nurse after Wendy was a magician with a syringe who could always find a vein when no one else could. I swear she could draw blood from a rock. She played the role of a surrogate grandmother to me, always bringing me a stuffed animal or some pastry she had cooked at home. I loved her delicious blueberry fluff. She was overweight, jovial and, yes, she had big boobs.

My nurse buddies took care of everything. If I needed pain medication and the anesthesiologist in charge of my case forgot to write the order or couldn't be paged, they would give the opiate drug to me via my IV and then record it as "wasted" from being dropped on the floor. Always my blood labs were drawn by one of my buddies through my IV line, much to the chagrin of the phlebotomists who felt useless around me.

There were many other nurses and clinicians who passed through the SPU without knowing how my buddies and I played practical jokes on one another. Eileen and Carrie usually worked as a team surprising me with their funny stunts. If I requested my nose cannula be replaced with an oxygen mask, they would cover my whole face with a clear plastic bag and shout, "Oxygen, we'll give you oxygen!" It really looked like they were suffocating me, scaring the hell out of a young doctor who passed by my bed. Their best joke, or maybe I should replace that word with incident, was when they put a blood pressure cuff around my scrawny neck. A pecker checker, oops, sorry, I mean urologist, ran over to my bed, shouting, "What are you doing?" When he noticed we were all laughing, he stopped in his tracks and turned away mumbling to himself.

Dad loved all our joking around. He firmly believed the old adage that laughter is the best medicine. Sometimes, I would get carried away, engaging in a little horseplay. When Wendy sprayed water on me with a syringe (I think it was water), I sought out my revenge an hour later, dousing her with a cup of ice-cold water. Since no one knew what was going on, they gasped at what I had done, until she laughed and congratulated me for getting even. As always, Dad was proud of me. I think Wendy was, too.

Like me, dad listened to my buddies talking with each other and over time picked up a lot of medical slang. He had a ball talking with them using his newly acquired, esoteric terminology. He tried so hard to be funny and, on rare occasions, he was. He would say things like: "My rear admiral (proctologist) discovered grapes (hemorrhoids) in my butt." He also enjoyed talking to the other

patients whenever he could. Out of the 24 beds in the SPU, there were always a few with people who weren't in unhappy moods. He would approach them, asking how they were doing and what they were there for. I have no doubt that many of these patients thought he was a hospital employee of some sort. If I thought he was being obnoxious or bothering a patient, I would kick my feet up and down violently and he would run over to me. My buddies knew I wasn't having a "happy foot" episode (seizure), causing my dad to wonder why they didn't respond. "Dad, can you get me some water?" I asked with a pouting smile, obviously doing okay.

21. LAS VEGAS

A week before my seventeenth birthday, Jane Doe called and invited me to go with her to Las Vegas to celebrate. We had been keeping in touch with intermittent emails, but she never let on she was planning to take me on a new trip. All I knew about Vegas came from movies and my imaginative, know-it-all, youthful mind. I envisioned mean-looking gangsters lurking behind card tables and whores wearing low-cut, red dresses. I was so happy to be with Jane again, I didn't care if she took me into the bowels of Hades. Besides, Dad would be coming along to protect me from the evils of "Sin City" and to dole out my medications at the prescribed times. Mom and Tommy didn't come with us, preferring to go to a comic book convention instead. Oh, well.

As the G4 flew over nighttime Las Vegas and banked toward the airport, I looked down at a dazzling, jewel of a city, lit up with thousands upon thousands of shining lights. I had never seen anything like it and I became awestruck. Then I realized that this city, carved from the hard desert earth, really was, as Jane said, the entertainment capital of the world. I couldn't wait to scramble out of the G4 and taste the eclectic atmosphere of the city that never sleeps.

Jane's assistant, Susie, stepped out of the plane first, exclaiming, "What happens in Vegas, stays in Vegas!" I wondered if she had a boyfriend who had no idea where she was or what she was doing. Later, I learned she was just spouting out a well-known aphorism. If a common denominator existed between Jane, Susie and I, it would be our insatiable desire to have fun. We had the whole weekend to let ourselves go and since Mom wasn't around, I intended to find out what it was like to get drunk. To hell with my health, I thought. If I got sick, I would bounce right back.

A limo took us to the Windfall, a popular hotel/casino designed to look like a pirate's treasure chest. Aside from the check-in lobby, restaurants and fancy shops, the entire first floor held a casino larger than a football field. I hurried up to the sixth floor suite Jane had provided for me, drained my bladder and scooted back into the elevator and back down to the casino. I spotted Susie at one of the bars sipping on a cocktail and playing video poker. Dad and Jane were lost somewhere among the crowds in the casino. I made my way through a labyrinth of slot machines like a rat hunting a morsel of cheese, motivated by my desire to have one of them buy me a beer.

Dad and Jane were sitting together at a blackjack table and I figured they were winning since they seemed too happy not to be. I picked up Dad's bottle of beer and kept it for myself. Some guy in a suit looked at me for a second until Jane whispered something in his ear. After that, he ignored me. Jane was a frequent visitor and quite well known at the Windfall. She was a high roller and a big tipper. Once identified as a member of her party, my age would no longer be a problem. I freely ordered drinks on my own without anyone asking to see my ID. I never knew how I got cleared so fast, from one end of the casino to the other. If it wasn't telepathy, then they must have had one hell of an audio-video communications system.

The beers I drank started to make me feel that same warm and fuzzy sensation I got at Disney World from the wine. Since I had insomnia for a friend, I had no problem staying awake from dusk to dawn. Somehow, Jane, Susie and I later found each other at a roulette table and from that point on we stuck together like glue, laughing at everyone and everything without inhibition. We were a modern, all-girl version of the three musketeers, substituting beer bottles for swords. Dad had all he could do to keep up with us and watch out for our welfare. The casino security guys also kept a discreet eye on us. Woe to any perverts who tried anything funny with any of us. No one came near us though, not even an old drunk. Our blanket of protection was never tested.

Later that afternoon, I woke up feeling my first hangover headache. I vaguely remembered dad propping me up in the elevator and half dragging me, my arm around his neck, all the way into my suite. I swallowed some pain pills and eased myself into the hot, swirling water of the whirlpool tub. I became so relaxed and weak from the massaging water jets, it took all the effort I could muster to crawl out before drowning. My pacemaker kept my heart going.

We all met for dinner and the wine began to flow. Jane gently coerced me into trying one of her favorite cuisines, some kind of a clam, dipped in a putrid

tasting sauce that almost choked me. I turned red and coughed for several minutes, scaring everyone into a near panic. Soon all was well again, and I enjoyed some delicious caviar, washed down with red wine. A yellow cake smothered in strawberry frosting was put on the table and everyone began singing Happy Birthday to me. Since we were all feeling somewhat inebriated, everyone got up for a spontaneous group hug, wobbling on our feet like rugby players in a scrum formation. Scrum. What an interesting word. I like it.

A black limo met our motley group in front of the Windfall and we headed downtown to a rock concert at an outdoor stage that sealed off the entire end of a street. The limo pulled up right behind the stage. Jane and Susie met the band members like old friends. I was introduced to the lead singer who took my hand and led me up onto the stage. Flood and spotlights assaulted me with unrelenting intensity. Through shrunken and reddened eyes I could see a whole street full of people staring up at me. I had too much wine in my veins to feel stage fright or to care about how my ascites made me look pregnant. The lead singer and I formed an impromptu duet, sharing the same microphone and dancing to the beat of the music. Fortunately, the sheer volume produced by the band's amplifiers drowned out my voice. Only my body language and dancing around made it look like I knew what I was doing, which I didn't.

After the song, I made my escape to the back of the stage where Dad, Jane and Susie were jumping up and down with excitement over how well their surprise to put me onstage worked out. My pulling off a performance like a pro turned the surprise back at them. I have to confess, I could never have done it sober. It's amazing what you can accomplish with an alcohol-numbed brain. Capping off all the excitement, I suddenly felt nauseous and puked my guts out. The last and final surprise came from out of my mouth.

22. ON THE LIST

Being evaluated and undergoing various procedures at Mammoth wasted almost a year, decreasing my life expectancy time line for nothing. It seemed as though I was some kind of commodity being bounced around within the medical business world rather than a sick patient receiving proactive care. Sorry if I'm coming across as cynical. If you couple illness together with a suspicious nature it's easy to be that way.

Pacific now became my only hope. Unlike Mammoth, they had a comprehensive transplant program where all the different organ transplant

departments worked together. What Mammoth saw as problems or reasons not to place me on their transplant list turned out to be non-problematic with the Pacific physicians. My case presented them with a unique challenge, which they enthusiastically accepted.

Once again, I underwent an extensive battery of cardiac and hepatic tests to evaluate my need and urgency to be transplanted. I sensed as though everyone, from the desk clerks to the surgeons themselves, wanted to help me live. The friendly, caring attitude of the Pacific physicians put my mind at ease and lifted my spirits. Like a boxer who fights better with positive-minded supporters in his corner, I began a new round in my fight for survival, determined to hang tough. My mind and spirit versus my body entered into a contest for dominance. If I couldn't control destiny then I would damn well try to influence it.

Before the formal decision on whether I would be placed on Pacific's transplant list could be made, I needed an updated, heart catheterization assessment done. This would give the surgeons a picture as to what they would be up against. Even though all my medical history records had been reviewed extensively, the Pacific physicians wanted their own road map laid out before they would consider slicing my body open with their scalpels. The cath showed multiple collateral veins running twisted paths all around my heart like tangled spaghetti, which lit up like a Christmas tree under the contrast. The cardiologist who performed the procedure said he had never seen anything like it. The majority of these nonessential veins were sealed off during the procedure and left to wither away.

The three major players in my soap opera life at Pacific were: Doctor Cirrus, the liver transplant surgeon whose hands strangely had liver spots resembling the shapes of amoebas; Doctor Yezman, the heart transplant surgeon who resembled a Mr. Potato Head toy; and bear-like Doctor Akumin, the esteemed Director of the Comprehensive Transplant Program. From the perspective of my youthful eyes, he appeared older than old, a living, breathing human fossil. No disrespect intended.

These three highly skilled physicians had the courage to accept the challenge to transplant my heart and liver in spite of what seemed to be insurmountable odds for success. Usually, when a patient like me comes along with the odds stacked against surviving transplantation, physicians just shake their heads and emphatically say no. Unfortunately, a negative decision like that meant it would be just a matter of time before a patient's body reached room temperature and became only good for parts. Considering the acute shortage of

available donated organs, it is not a good idea to waste them on (or should I say in) someone who may not live through an incredibly difficult surgery.

Yet, the Pacific physicians not only trusted their own skill, they believed in me. Perhaps, once again, my youth, attitude and fighting spirit aided in the decision to place me on their transplant list, although I like to think it was my charm. Inotropic drug therapy was waived due to my adverse reaction history. My chemical dependency on opioid painkillers was considered a non-issue. Intravenous immunoglobulin therapy (IVIG) would downgrade my antibody problem. The danger of bleeding during transplantation because of my previous thoracic surgeries would be real, but that alone was not considered reason enough to turn me down as a transplant candidate. The most compatible organ match possible and a life long regimen of anti-rejection drugs would all but guarantee me an extended life.

At long last, being placed on a transplant list brought immense relief to my parents and instilled in me yet another new spark of hope even though I could still die before matching donor organs were found. My muscles were slowly wasting away from protein depletion while edema continued swelling my legs. I was quite a sight with my elephant legs, stick figure arms, protruding belly and pretty face. In spite of being self-conscious, lacking self-esteem and angry, I still wanted desperately to live. Maybe, by not wanting to commit suicide it meant that I was more of a sanity avoiding, nut case, rather than the other way around.

I hid my inner turmoil well and even smiled brightly when I first met Doctor Akumin. I knew that charm often worked to my advantage. I mean, if you were a doctor wouldn't you try harder to help a charismatic angel than a depressed brat? I'm not a brat, but not an angel either. I like to be funny, more to take my mind off my afflictions than only because I believe laughter is good medicine. When the doctor realistically told me that the wait for matching organs could take up to a year or more, I joked about getting a heart and liver from a tiger or a leopard. "That's xenotransplantation, my dear," he said with amusement. "Sorry, can't be done. If it could, wouldn't you rather be lion-hearted?"

"No, I like tigers and leopards more, especially snow leopards, or how about a dolphin? That would really be cool." I thought for a moment. "Instead of my body rejecting the animal's organs, they would probably reject me."

Doctor Akumin chuckled a bit then he became serious. "Sara, you know Lynn our transplant coordinator, right?" She was standing next to where Mom, Dad and Tommy were sitting. Our eyes met and we smiled at each other. "She will

be your main contact here. Let her know if anything changes—anything. If you catch a cold, have chest pain, throw up, anything at all. Okay?”

I didn't concern myself with the how or what to do instructions. I knew Dad would take care of everything. He would be my primary caregiver and supporter, backed up by Mom and Tommy. His cell phone number would be called if I didn't answer mine, if and when a compatible heart and liver became available. Being on a transplant list with Dad watching over me gave me a profound sense of relief. Knowing I had a real chance to live made a huge difference in my disposition with the weight of worry all but removed. What my reaction would be if actually called, I didn't know.

I struggled out of my chair and gave Doctor Akumin a goodbye hug. He reminded me of a giant panda with a soft tummy. Oddly, his office was decorated with potted bamboo plants. When I told him I liked bamboo, he told me it was related to grass. Mom, holding back a tear, gave the doctor another hug right after he presented me with a six-inch tall, potted bamboo shoot.

Soon Mom, Dad, Tommy and I were on the clogged freeway driving home. Pacific Coast Memorial Hospital disappeared in the hazy smog behind us. We all remained in deep thought, unusually quiet during the five-hour drive home. I clutched my bamboo shoot and thought about my kitty, Luna, who waited anxiously for my return. We were all feeling too sentimental to celebrate. There was no need.

23. BOYFRIEND

Oakden's SPU is a large room with a nurse's station in the center. One half of the room is set up for incoming, pre-op patients and the other half for post-op patients. All the beds are rollaways separated by movable curtains, which provided a fleeting sort of privacy. Most of the patients came in during the morning and left that same afternoon. Occasionally, due to an unexpected complication, a patient would end up admitted to the hospital for a longer stay.

My visits for paracentesis procedures were so frequent and routine that the SPU became like a second home to me. My nurse buddies were all ecstatic that I was officially listed for transplantation even though it was at another medical center and they continued to dote on me like mother hens. One of them (I never knew who for sure) brought to the attention of the others that I didn't have a boyfriend. I already had enough mental activity mangling my brain without adding thoughts of boys to mix my mind up further. Since I didn't feel any of the raging

hormones that seemed to beset teenage girls, I decided I was either immune to the wiles of stupid boys or my medications had suppressed any desire to be around the male animal, with the exception of Dad and Tommy

My tap had pulled out six liters of ascites fluid and I slowly regained consciousness. The propofol and versed were wearing off and Wendy injected 50 cc's of fentanyl into my IV for pain, after checking my vital signs. Emma was writing in my chart while Eileen and Carrie conspicuously watched me from the nurse's station. As I tried to clear the cobwebs from my drugged brain, I noticed the curtain between my bed and a neighboring patient had been pulled back. I was about to call my Dad to come over and close it when I heard a young man's voice.

"Hello," the voice said. "I saw you on TV. You're Sara, right?"

I replied half-heartedly, "Yeah. I get interviewed a lot lately for some reason." Then I noticed my nurse buddies making a hasty retreat and I realized they had set me up, playing the cupid game. I judged the boy to be in his early twenties and since he had a sincere ambiance about him, I felt comfortable talking with him.

He spoke again. "I'm Mark. They just did a biopsy on me. I've got CF and need to have oxygen all the time." He pointed to the oxygen cannula in his nose.

"What's CF?" I asked out of ignorance.

"Cystic fibrosis. It's a lung disease. Makes it kinda hard to breathe," he replied, lowering his eyes. "I need a lung transplant. I'm on the list here at Oakden."

"Oh," I said simply, my tempered-down acumen making me unable to respond any better. He shyly raised his eyes to look at me and we exchanged uneasy smiles.

Partly out of empathy, Mark and I began a friendship that would become much more. Rather than complicating my nearly scrambled mind, talking with him helped smooth over the jagged edges of my negative thoughts. I felt happy. Except for the differences in our medical conditions, we had a lot in common. Healthy people could never fully understand what our bodies and minds had to endure. In spite of severe physical limitations, we both had a strong, spiritual desire to survive, to live, no matter what. The first drop of emotional glue that began sealing our relationship wasn't from using each other as crying towels or from empathy alone. It was from our discovery that we were both animal lovers and bleeding-heart environmentalists. Mother earth needed us.

Mark wasn't the kind of guy who thought of girls as sex objects. Who knows? Maybe that's more abnormal for a boy than normal, but it suited me just fine at the time, considering the fact I was hardly a sexy-looking girl with my swollen and scarred body. I guess the same thinking held true for me as well, because it didn't matter to me that he had to drag an oxygen bottle around, alongside his own emaciated body. I did wonder about how we would handle sex if our relationship ever reached that point. The way we looked wasn't much of a turn on for either of us. Oh crap, I don't want to evoke any pathos so I had better shut up.

Of course, there were a few things that we didn't like about each other, but on a scale of overall compatibility it amounted to no significant weight at all. Once in a while, however, Mark behaved as if he didn't have the sense God gave a dung beetle and I had to hold back from slapping some sense into him. It is said that a sucker is born every minute and he was certainly one in every sense. He believed and trusted everyone to the point of extreme naivety. Because of this, he was always getting scammed and unable to hold on to his money or possessions. I was just the opposite and ended up becoming his watchdog. Needless to say, he believed what I told him and trusted me unequivocally.

Mark and I began seeing each other—a lot. His father had passed away from lung disease a few years earlier and he lived with his elderly mother in an apartment two blocks from the hospital campus. They lived modestly on a monthly income derived from his father's life insurance and her social security. She was overjoyed that her son had found a girlfriend, something she didn't expect would ever happen. Still, she feared he would one day leave her alone either by dying or going off on his own to face the world. Her paranoia was partly relieved when I promised I would never take him away from her, no matter what. She was such a sweet lady it was impossible not to love her.

Mom and Dad were somewhat leery of Mark at first. He looked as if he would keel over and die at any moment, but his resilience and inner strength kept him going. When they first met, Dad feared his hand would break away from his unusually frail arm when he shook it. In time, my parents saw that we had a unique and beneficial relationship. They were impressed with Mark's positive attitude, sincerity and compassion. I knew that when Tommy came home from college and met my new boyfriend, he would like him, too. Even my kitty, Luna, after sniffing his oxygen bottle, curled up next to him on the couch and purred approvingly.

Mark and I loved going to the beach to watch the Pacific sunsets. Unfettered by his oxygen bottle, we waded in the surf holding hands. I enjoyed stepping on those bulbous sacs that were part of the washed up kelp, making them pop open. We stopped walking, held each other in a tight embrace and tenderly kissed for the first time. A light rain began to fall. It seemed as if God and nature had blessed us. We had become consecrated soul mates. It was magical.

24. CONTEMPLATION

At the formidable age of eighteen, I began 2006 with the mindset of a typical pre-transplant patient, full of mixed emotions, always wondering with apprehension when that special phone call would come from my transplant coordinator, telling me they had a compatible heart and liver and to get my panicky self over to PCMH right away. Whenever my phone rang in the middle of the night, I would jerk awake and break out in a cold sweat. If the call turned out to be a wrong number, I would curse at the unknown caller like an irate bitch for scaring me awake. Didn't they realize that calling my number by mistake caused me to have a massive adrenalin rush? Of course not, that wouldn't be possible, would it? Sorry, wrong number callers aren't necessarily brain dead, unless they are trying to contact God using the 911 number.

Mark and I made it a point to never call each other between midnight and seven in the morning. We had similar worries about how we would react if and when that all-important call came. We rarely talked on the phone for more than a few seconds at a time not wanting our transplant coordinators to get busy signals. Once notified to come in for transplantation, time is of the essence. Harvested organs can't just sit around in a cooler indefinitely. When at home, Mark was minutes away from Oakden while I was hours away from Pacific, unless we were at the beach, which reversed our time lines.

We spent so much time at the beach that we developed a sort of symbiotic relationship with the sand fleas, to their benefit, not ours. Even though I provided a juicier meal with my edema-filled flesh, the fleas preferred biting Mark's skinny legs. Maybe, I was too toxic or, like a child, they didn't want to eat what didn't look good. That's just great, even the sand fleas found my body unattractive. By keeping away from the dunes and staying closer to the tide line, we cheated the tiny predators from dining on Mark's tanned and tenderized skin.

“God, the water’s cold,” I said, shuffling my feet through the surf. I was looking for seashells, but all I could find were sand dollars. I picked up a wet one and stuck it in Mark’s face.

“Damn, that stinks,” he said, obviously annoyed with me. “Everything kinda smells today. I bet it’s that sewer runoff polluting the water.”

“Yeah, that’s why no one’s in the water. Not even surfers are out today.” I replied with a scowl.

We automatically stopped wading, opting to walk on the dry sand instead. We never walked very far, Mark couldn’t, his breathing became too labored. Most of the time we just plopped down on the sand, watching the waves break and dissipate on the shore while we cuddled together and contemplated about why things were the way they were—or weren’t. We did more deep thinking together than talking. Talking used up too much of Mark’s oxygen, so I did most of it, adding additional credibility to the theory that women talk more than men. Since I am a member of the female gender, it’s my prerogative, right? Much of what we contemplated was profound, at least, we thought so.

Watching the waves undulate up and down against unseen currents reminded us of our own lives. For us the high crests weren’t so high and the low troughs were quite low, indeed. We knew our lives would end up like the waves, breaking and dying on the shore. It was inevitable, with the only question being when. Which one of us would be transplanted first, if at all? Which one of us would be the first to find peace through death while the other mourned? Please don’t misunderstand our musing. We were neither pessimists nor optimists, but rather, realists. It wasn’t negative thinking at all. We would rather worry about a cut finger getting infected than about death. Sweat the little things you can do something about, not the big things you can’t do anything about. Worrying about big things is the killer, the depression maker. We lived one day at a time and we fought to survive one day at a time. Each new day was a blessing and a reminder to never give up. Fate and the future belonged only in the realm of our spiritual destinies.

I asked Mark, “Are you scared to die?” A flock of gulls drifted close enough to see if we had any morsels of food worth stealing. We didn’t and they flew away.

“Used to be. Not any more,” he replied, watching the gulls pitch and yaw in the sky. “We all end up dead anyway so why care about how long or how short our lives are. After we’re gone, we won’t know the difference anyway. I mean, it’s like before we were born, non-existence, nothingness.”

“That’s true for our physical bodies, not our souls,” I replied pensively. “I like to think there’s some kind of life after death, like a heaven, another dimension or something—just different. Maybe I’m being romantic, but I like the notion that our spirits become all the stars in the universe. We’re all, like, star dust anyway.”

I think more for the sake of argument than anything else, Mark replied, sucking air, “If we are the way we are and can’t change than why be concerned at all? Shouldn’t we just join the masses in this dog eat dog world, with a ‘survival of the fittest’ attitude? Just believing what we want to believe and not giving a shit about anything else?”

I held my hand up warning him not to talk so much. I didn’t want him to run out of breath. “How can we know what’s real, what’s true?” I asked. “Why does every single religion profess that their way is the right path to God and that all other religions are wrong. There are even divisions within the same religions. It’s crazy. It’s incredibly arrogant!”

“Sara, truth is only a point of view, with hypocrisy thrown in for spice.”

“Yeah, but why do people justify doing bad things in God’s name? Like terrorism and war. It’s mind boggling and senseless. It’s insane to think that a benevolent God would sanction killing and bless you for it. I gotta believe more people are sanctimonious than not. Sometimes I feel ashamed to be part of the human race.”

Mark rubbed his eyes, inhaled a lungful of ocean air and increased the output volume on his oxygen cylinder. He replied, “Everything in nature needs to be in a state of balance. Only humanity has managed to upset that balance with a voracious appetite to consume our once pristine planet down to its bare core. Maybe our killing each other in large numbers helps keep nature in balance, although we’re outrunning nature’s, or God’s, design by overrunning the planet exponentially. Ugh! Thinking about this stuff makes my head hurt!”

For an hour, we sat with a welcome silence, clearing our minds. Our home star, the sun, grew redder and dropped into the horizon creating a magnificent sunset. Scattered clouds began glowing like embers of cotton on fire. A lone meteor streaked across the sky cutting a path through the darkening twilight. Perhaps, it was a sign of hope.

25. MOSTLY A BAD YEAR

2006 turned out to be a difficult year. I structured my restrictive life around my paracentesis procedures and relatively pain free days. I was getting tapped every seven to ten days and it was beginning to undermine my will to keep fighting. I prayed more often than a nun to be called in for my heart and liver transplantation. Patience has never been one of my qualities and waiting for the gift of life seemed overwhelming. Mom and Dad never stopped injecting positive thoughts into my mind, which, in turn, kept my soul patched up and animated with energy. I have been told that I possessed extraordinary mental fortitude, but in truth, most of my strength came from Dad motivating me. Alone, I would have become disheartened, accepting the “survival of the fittest” law of nature, which in my case meant non-survival of the non-fittest.

My Advance Health Care Directive made Dad my legal agent for making health care decisions on my behalf should I become medically unable to do so. It also stated my desire to pull the plug if an irreversible event happened. I had no desire to be on life-support if I went into a vegetative state before finally passing away, esoterically known as a “slow code.” I’m not selfish enough to place a long-term emotional burden like that on my family. If some kind of realistic hope actually existed then I certainly wouldn’t want to lose life support, otherwise, just forget all the arguments about what’s ethical and release my spirit and let it fly free.

At this point in my life, I found myself on the down side of my up and down, emotional, roller-coaster ride. Yep, this so-called, inspirational survivor had bouts of negativity and even sobbed from self-pity from time to time. I didn’t like myself getting all messed up with negative thoughts so I eventually shrugged them off and battled my way back to having hope again. Most of the credit for my being able to fight off depression and to never give up again goes to Dad, who would say corny things like, “The world’s a better place with you in it.”

There were various reasons for this being a bad year for me, besides the seemingly endless waiting on the transplant list. Every time I visited the hospital as an outpatient some little thing happened to upset me. Scissors cut my arm during a PICC line dressing change. The removal of tape pulled away a layer of my skin from my abdomen. Those kinds of things were happening too frequently. I missed Tommy while he was away at college. He would soon have a degree while I had yet to earn a high school diploma due to my miserable attendance record. Or should I say my non-attendance record? Maybe I’ll find out if there is any truth

to that trite old adage that ignorance is bliss. I never did feel very blissful, though. I also missed Jane terribly and hadn't seen her since the Las Vegas trip. She was in Europe and her emails were scarce. Worst of all, Mark's lungs were deteriorating and he became hospitalized. He described his breathing as suffocating with a plastic bag over his head. He would not survive much longer without a lung transplant. The clock of life was ticking away on a special guy who I had fallen in love with.

I underwent laser throat surgery to remove scar tissue caused by the scraping of the endotracheal tube inserted during a recent, abdominal hernia repair. It made my voice sound like the hee-haw of a braying donkey. Heart and liver biopsies are never fun either, but a bone marrow biopsy is especially not fun. A large gauge needle was shoved into my lower back, upper butt area into something called the iliac crest. Before the biopsy needle stuck through my flesh and bone, the doctor prepared to inject lidocaine at the site. He held up the syringe and test squirted the local anesthetic and made a direct hit into my nurse's eye. "Shit!" she exclaimed, making a dash to the nearest sink to flush out her eye. She quickly returned to assist the now uneasy doctor. She was a trouper!

Setting records for the number of times a patient underwent a paracentesis procedure for intractable ascites wasn't something I aspired to do. Doctors Hershe and Blue tried to slow down the fluid buildup with another round of IV diuretic therapy and a prescription for pills that would make me pee a lot. The pills took several hours to take effect, then, suddenly I began draining my bladder like a pot-bellied, beer drinker. Once it starts, it's every five minutes. The stream team (urologists) would have whole-heartedly approved. I could have used one of those Foley catheters, but I abhorred that for obvious reasons. I learned to never take a pee pill whenever I would be away from a convenient toilet. When traveling on a freeway, it is unwise to not have a handy container available. Empty coffee cups are too small to suffice during an urination emergency. I envied men who only had to whip out their dicks and conveniently piss wherever they wanted.

During one particular pee emergency while in the SPU, I was sitting on the commode in the "patient use only" bathroom, looking at pictures of sewage treatment facilities in an outdated, trade publication for water district engineers. "Who in the hell brought a magazine like this in here," I thought disdainfully. Then I saw a big, ugly, shiny brown roach making its way across the floor—toward me! The roach sensed my presence (my warm body?), twitching its antennae nervously in the air. It didn't see the rolled up magazine clutched tightly in my

hand and I doubted if it sensed danger in its ill-fated attempt to scurry away and hide. It probably moved solely in response to an instinct imprinted in its genes. It didn't matter that it belonged to a species that had survived against all of earth's cataclysmic events for thousands, perhaps millions, of years, which wiped out myriads of other life forms. Its own chance for survival came down to one desperate split second as it came within my striking range. Then, swiftly, I ended the roach's life on this earth, smashing its shiny brown body flat on the bathroom floor. It certainly wasn't the fault of the roach to be such a creepy looking insect, making it a target for death. The balance of nature in its indifference was not a factor either, since I had no intention of eating such an excellent source of protein. Good riddance, I say.

I got the hell out of the bathroom as if it were a crime scene, climbed back into my bed and watched to see what would happen when the next patient went in. Oakden's SPU was about the cleanest place around, making me wonder how a big roach like that could show up. The hospital even kept the air conditioners running overtime to keep the temperature cold enough to make even the bacteria bugs unhappy. I surmised that the roach was not a happy critter and by killing it I ended its misery. The question still remained in my mind. How did it get here? Maybe, it came in via the ER in the clothes of a "reeker," some patient who resided under a bridge somewhere. Maybe, it came from a food delivery to the kitchen, frozen along with some turkey parts, thawed out back to life and brought to the SPU in a patient's lunch tray. I admit my hypotheses may be flawed, but one thing was certain, a boring magazine served a useful purpose. Perhaps, I may have upset nature's balance in an infinitesimally insignificant and indifferent way.

26. ROLE REVERSAL

The year 2006 waned toward its final month and my nineteenth birthday without becoming any better. Dad and Mark were both hospitalized at Oakden at the same time. Dad would recover and get out. Mark would not. I visited both of them daily with Mom, except on the days when my ascites fluid was drained. Ironically, on those paracentesis procedure days, we all wore the same not-so-fashionable and breezy-in-the-back hospital gowns. Usually, Dad undertook the role as my principal caregiver and advocate. Now, our roles reversed and I became his caregiver. Mom was there, of course, but I liked to think I was his main girl even though I was hurting most of the time and unable to do that much

for him. Mom ran around like a gopher, going for this and going for that, while I did what I considered the most important job of all, staying at his bedside.

A week previously, during the night, Dad began experiencing severe, lower abdominal pain and Mom and I took him to the ER. A CT scan confirmed deep vein clotting and intestinal infarction. Twelve inches of his bowel were surgically removed and blood-thinning therapy was started to dissolve the life threatening clots. Once again, I was terrified that I might lose him. How could they cut away a section of his bowel and reconnect it again? How could they correctly restuff his uncoiled guts back into his body? I had no idea, so I worried, feeling like I would swallow my aching heart. I even worried about the unlikely scenario of half-digested food leaking out from his reattached intestine if it didn't grow back together correctly.

Dad's stay lasted three weeks. On the last week, he had all his drainage tubes removed and was allowed to walk around in the hallways with a physical therapist. Tethered to an IV pole, he shuffled back and forth like a slug, building back the blood flow in his legs. Getting out of bed and moving around made him feel a whole lot better and he enjoyed the extra freedom. Alone in the bathroom, he just finished shaving with his electric razor when he started to pass out from ventricular fibrillation. His ICD zapped him with a large jolt of electric current, knocking his heart back into sinus rhythm. He was being monitored at the nurse's station since he was on the telemetry floor and two concerned nurses rushed in to check on him. Realizing what had just happened, he sheepishly uttered the words, "Holy shit."

It took me a while to get used to the fact that you can't be modest if you're a patient in a hospital. Dad never did get used to that undeniable fact and still felt uncomfortable about having his manhood exposed to what seemed to him to be every employee in the hospital with an ID badge. Rather than feel dirty and sweaty he would allow himself to be washed by the nurse assistants. Fortunately, his environment and the fact that the females scrubbing him were not hot-looking chicks, he never became aroused. I wondered if hospitals secretly gave patients a drug to counteract erections. Naw, no way!

Often, physical therapists can become over zealous and push you too far, resulting in a setback. I had that experience after one of my open-heart surgeries, so I really watched how hard and fast they pushed Dad to walk. Eventually, his nurses, unaware of my own medical status, allowed me to take him on his walks. The only restriction was not to go beyond the telemetry range. We decided to break that rule and go further, like any pair of mavericks would do given the

opportunity. We ended up taking an elevator three floors down and sauntered into the SPU, pulling the IV pole along as fast as possible on its little wheels without toppling it over. My surprised nurse buddies surrounded and hugged us, happy to see us being so active. Then we were justifiably scolded for leaving the telemetry ward and told to get our butts back before getting into trouble. Right or wrong, the freedom felt wonderful. I thought about taking Dad to the cafeteria on our next venture out so he could order whatever food he wanted, provided I selfishly decided on what the dessert would be.

Watching Dad recover so rapidly soothed my emotions, but all those good feelings were blunted by Mark's worsening condition on the floor above. While I was allowed to be with Dad constantly, I could only visit Mark for a few minutes each day, pretending to be his sister. Since he was in the ICU only members of his immediate family were allowed to see him. Whenever Dad slept with Mom close by, I would go up and try to see Mark. His mom was always there in the ICU waiting room and we tearfully hugged each other in silence. There was nothing more we could say to each other so we quietly prayed that donor lungs would be found in time to save his life.

The day before Dad's discharge from the hospital, Mark's mom did have something to tell me. "I think Mark has finally given up," she said. "He's tired and can't breathe. He doesn't want to live anymore. This morning he yanked out his IV."

"I'll talk to him," I said, my voice trembling with alarm.

"No, you can't, Sara. He's not awake." Grief-stricken, she began sobbing. She handed me a folded piece of paper with my name on it. It was a note for me that Mark had given her in reference to a discussion we previously had about stem cell research. I don't know when he wrote it.

Sara - My take about life re. stem cell research - Animal (human) life matters at the beginning point of consciousness, before that, life in a non-conscious state (not to be confused with unconscious) is equal, for example, to plant life and to end it would be no different than cutting down a tree or picking a flower. To argue otherwise is fine, but then hadn't we better stop destroying all the flora on the earth? How can we be so arrogant and hypocritical to think one life form is more important or sacred than our own? Life is life, or is the ethical difference dependent on whether or not it is conscious or non-conscious?

I felt an impending doom. My mind began rambling in a rapid tangle of thoughts: "Was Mark really about to die? Has he already died? Why is this happening? If only there were more organ donors. Mark is one. Some of his

organs are still good enough to save lives. Mark and Tommy haven't met yet. God, I loved the guy. If only we could have made love, I would have."

At the age of twenty-five, Mark exhaled his last breath and passed away, before any suitable donor lungs could be found. Had more people, who tragically lost their lives, been organ donors, his life would have been saved. I couldn't help but wonder how I would fare. They moved his body into that eternal care unit, better known as the morgue, on my birthday. I missed him terribly, but I needed to go on without him. I had to. Some day, after my sobbing has ended, the sadness in my heart along with his memory will fade from my mind into history. It always happens that way, after all, dead men need no family or friends—no one.

27. MOON SIGN

On January 31, 2007 at 4:30 in the morning, Dad's cell phone played a rhythmic tune from the soundtrack of *Kill Bill*. The caller was Lynn, my transplant coordinator at PCMH. "Sara isn't answering her phone. We have a possible heart and liver match for her," she advised. "Start coming in right away. Keep your cell phone on, in case we have to cancel her surgery before you get here."

Dad gently shook me awake, telling me I needed to hurry up and get dressed. I may finally be getting a heart and liver. Sometimes, for any number of reasons, it turns out to be a dry run and you have to turn around and head back home. After waiting for a year and two months, my first call to come in happened when I was too sound asleep to hear my own cell phone. I stiffened with apprehension. A flood of tears drowned my now wide-open eyes. I knew I had to go since my life depended on it, yet, the thought of undergoing such a huge surgery put me in a panic mode. I thought it a terribly monstrous thing to be awakened from my dream of swimming and frolicking with a pod of bottlenose dolphins. With Mom's insistence, I managed to get dressed. I put on a black blouse, black stretch pants and a pair of black sneakers. I looked like I was going to a funeral and I thought that I might be—my own.

In my heart, I knew I had to get myself in gear and move my rawboned body with its bulging tummy out to the car without delay. Yet, I balked, like some headstrong horse deciding at the last moment not to jump over a hurdle. Dad and Mom each grabbed hold of one of my arms, half-carrying, half-dragging me to the car. Having drained my tear ducts dry, my eyes rolled in their sockets, turning bloodshot from lack of lubrication. I coughed, wheezed, choked on my saliva and almost puked. What an example of bravery I turned out to be. My obstinance was

shameful and it started making Mom and Dad pretty upset out of frustration. Once in the car, I knew there was nothing I could do to stop the wheels of fate from turning. I hunched over, burying my head in my arms. I overheard Dad telling Mom, “You’d think she was heading to the guillotine to have her head chopped off.”

It was dark, with sunrise still a few hours away, as we headed west down the freeway toward Delta City. Soon enough, the rush hour traffic would start slowing us down to a stop-and-go crawl. We had several hours to get to the hospital and if there were no problems on the way we would make it on time. If something unexpectedly did happen like a traffic accident, a tailgate party in the carpool lane, a mudslide, a UFO landing, or a pack of Chihuahuas running amuck, then we would probably not make it on time. I knew Dad would break a few traffic laws if he had too, but even that wouldn’t be possible if our car became trapped in bumper-to-bumper traffic.

I watched how all the motorcycles easily snaked their way between cars oblivious to the heavy traffic. I knew that in the vernacular of transplant medicine they were called donorcycles, due to the high number of fatal accidents involving motorcycle riders with organ donor marked on their driver’s licenses. More often than not, when paramedics are called out to an accident involving a motorcycle it’s going to be a “Code Purple” run, meaning the victim is “smashola”, already dead. Rich and poor, young and old, believers and nonbelievers, we are all equal in death.

Here’s the thing. In spite of how scared and depressed I became, I bounced back. I’m not sure exactly how, but my spirit seemed to take the control away from my freaked out brain. Maybe, my attitude reversal was an example of that overused phrase, “fighting spirit.” Anyway, Dad’s pride in my newly established fortitude was based on one of his favorite sayings, an old Japanese proverb: “Fall seven times, stand up eight.” It’s amazing how you can get your shit together once your tears no longer blind you.

Like most teenagers, I wanted to fill my head with music and I scanned the FM stations, stopping at, *Don’t Let Me Get Me*, one of my favorite songs. Pink’s rhythmic singing was in tempo with my heart-racing tachycardia. Then, like the title of another of her hit songs, *Just Like a Pill*, I swallowed a sotalol tablet with a gulp of bottled water to slow down my heart rate. My mood was a far cry from the attitude I had when I first woke up, where funeral dirge music would have been more appropriate. Mom and Dad looked at each other with genuine relief written across their faces.

About halfway to PCMH, the ribbon of car lights tracing the freeway began to fade and blend with the first rays of light breaking over the earth's curvature behind us. A full moon, touching on the horizon, lay directly in front of us. The bright orb glowed an incandescent red-orange behind patches of parting clouds. It appeared as though we were driving right into it. It was ethereal, it was magical and it was profoundly spiritual. I felt a wave of warmth envelope my body. I didn't know if my mind had played a mysterious trick on me, or if I had encountered some sort of supernatural phenomenon. I believed it to be an omen telling me that everything would be fine.

As we drove onward, my "moon sign" gradually disappeared, having been swallowed up by the horizon. Even though I knew its light was a reflection from our own star, the sun, on the other side of the earth, I put aside my skepticism in favor of intuition. The position and timing of the moon was as though it had been ordained and at that moment I removed all remnants of my "feeling sorry for myself" attitude and ended my mourning for Mark, although I would not forget him right away. My life would go on, at least for a few more hours, anyway. Words from one of my favorite TV medical dramas entered my mind, "Everybody Lies." Did that include lying to myself, I wondered?

We arrived at PCMH on time.

28. TRANSPLANTATION

I wasn't admitted to PCMH via the ER like I thought I would be. Instead, an admitting clerk in the main lobby casually checked me in, as if I had arrived for a hemorrhoid surgery. The monkey-faced clerk plucked at her puffy hairdo that looked more like a termite mound while carefully scanning her computer screen to see if I was actually scheduled or not. Once satisfied that I was, in fact, the person having an imminent, double organ transplant, she pursed her lips and instructed me to sit down. "A volunteer will come and take you to your floor," she said haughtily. The smirking bitch did not fit the norm for how all the rest of Pacific's employees behaved. I thought she would be better suited to work over at Oakden's morgue since she had the personality of a cadaver. With all her hair plucking, I wondered if her disdainful attitude was rooted in discomfort from a head lice infestation.

In the pre-op room, I traded my black clothes for the familiar, not-so-chic hospital gown. If there was ever a garment that made me feel slutty, this was it. At least the "open in the back" design prevented the material from sticking in my

ass crack, which was okay since I wouldn't have a wedgie problem. Several pre-op nurses checked me over and scribbled data into my ever-growing chart. I signed a lot of liability releases and talked with my anesthesiologist. "No, I haven't eaten since yesterday. Yes, I recently drained my bladder."

Two surgical nurses wearing freshly changed scrubs came over to me and asked, "Ready, Sara?" Even with versed in my bloodstream, I turned white and tensed up. They never seem to give me enough of that stuff. It's supposed to make you forget, but I never do. Mom and Dad leaned over and kissed me. I could see tears welling up in their eyes as they told me how much they loved me. Then the nurses quickly rolled my gurney through a pair of swinging doors into the operating room. It looked to me like the inside of an alien spaceship. The surgical team resembled a group of blue and gray clad androids. "Oh, my God!" was the last thing I remember saying.

Two surgical teams spent sixteen hours, working feverishly to replace my heart and liver with someone else's. Then, finally, to the great relief and exultation of both teams, the nerve-wracking surgery was over and I was transferred to a special isolation room in the ICU. My ointment-covered eyes were taped shut preventing me from seeing the manifold web of lines, tubes and wires connecting my body to an array of life support equipment. This was life support at its finest, involving all my body functions—from blood flow to respiration, from temperature to waste removal, and more.

A highly trained ICU nurse adjusted more than a dozen powerful medications on IV drips, in dosages determined by reading multiple monitors. My body's metabolism depended on her skill and ability to navigate through a tangled jungle of medical devices connected to my neck, arms, chest, abdomen and groin. Half the fluids in my arteries and veins that shared flow space with my blood were drugs. The only part of me that wasn't connected to some monitor, drain or dispenser was my soul. I'm sure it would have been if a way to do so existed. I was, for lack of a better explanation, a quintessential zombie, in between life and death.

When the nurse removed the tape from my eyes, slivers of light gradually transformed into a larger, blurry vision of two figures hovering over my bed. Paper masks and hair caps covered all but their eyes. They wore paper gowns and had on latex gloves. I was unable to visually recognize them with the glazy film of ointment still coating my eyes. I sensed and *knew* it was Mom and Dad. I wanted to reach up and hug them, but could not. With that damn breathing tube stuck

down my throat I couldn't cry out, "Help me, help me!" Not that anything could have been done to relieve my discomfort.

During the night, while Mom and Dad slept sitting up in the ICU waiting room, my breathing tube was removed and I was allowed to suck some water out of those sponge-tipped sticks. Those things only absorb and hold a few drops of water, hardly enough to satiate my parched mouth and throat. What I needed was my favorite drink, a pina colada, and a long, bendable straw. Wishful thinking was the only thing I could do, nothing else. And think I did: abstractly and logically, shallowly and deeply, profoundly and frivolously. It is said that an idle mind is the devil's plaything. What about an idle body? Does that mean anything?

My arms were bandaged to plastic splints and tied to the bed's guard railing to prevent my IV lines from being accidentally yanked out. An involuntary nerve reflex made my arms thrash about even while under sedation. Slowly, my senses returned and I was able to gain weak control over my muscles. I felt Mom and Dad touch my hand and the side of my face with their latex covered fingers. I managed to whisper, "I love you," and wanted desperately to be picked up and carried back home. I missed being with Tommy and my beloved kitty, Luna. Most of all, I still missed Mark. It didn't seem fair that I received the gift of life from an organ donor and he did not.

During my first six days in the ICU, I recovered better than anyone had expected. My new heart and liver were as close to a perfect match as could possibly be hoped for. Doctor Akumin checked on me every day and never failed to talk to me about my kitty. He grinned when I told him Luna tried to chew on the bamboo plant he gave me. Then, without warning, my blood pressure suddenly dropped and I went into cardiac arrest. Before I passed out, I heard him scream, "Code blue, code blue! Get the crash cart!"

Regaining consciousness several hours later, I had that breathing tube back in my throat again. I had been reopened by an emergency surgery to repair a hemorrhaging blood vessel to my heart. This event frightened the hell out of everyone, especially Mom and Dad. When I coded, Doctor Akumin had to perform CPR on me, causing his hair to turn a shade whiter with each compression stroke. The pressure made the blood ooze out from my chest incision, saturating his latex gloved hands. The incident would have frightened me to death, had I been conscious. Oops! Did I just use an inappropriate hyperbole?

29. RECOVERY

Hot damn! After spending two and a half weeks in an ICU isolation room, I was transferred to a post-surgical floor. Even though I remained highly immunosuppressed, the stringent rules protecting me from getting an infection were lessened. I had a private room and, best of all, the hospital put a folding bed in my room so Mom or Dad could take turns staying with me all night. I felt like a clipped-wing canary moving out of a tiny cage into a larger one, where I had a little more air of freedom to flap around in. For the next thirty days, my freedom would increase in stages. First, sitting up in bed and then walking in the corridor with a physical therapist supporting me. Next, wheelchair trips to an outside patio with my nurse and finally, walking on my own with Dad around the hospital campus.

My body still had to deal with the side effects from massive doses of drugs suppressing my immune system. The toxicity of the drugs knocked out my kidneys, a condition known as acute tubular necrosis. I needed dialysis until my kidneys began to work again. If they didn't, I would have been very unhappy to undergo another transplantation. My blood was filtered every day, sometimes every other day, for three to four hours per session. An average of three liters of fluid was removed from my blood each time. At the end of the procedure my head pounded and my heart began racing. A transplanted heart usually beats faster because all the cardiac nerves are cut during surgery. When the rapid beating did not subside on its own, I underwent cardioversions to shock my new heart back to a normal rhythm. After three weeks, I began peeing frequently, a sign that my kidneys were "waking up." It also meant some drug dosages were being cut back. I was not on any diuretics.

Immunosuppressant drug therapy was necessary to prevent rejection of my newly grafted heart and liver. In addition to screwing up my kidneys, it induced impaired insulin secretion causing type II diabetes. I needed to have my finger stuck for a drop of blood several times a day. I would receive a shot of insulin in an amount determined by the glucose meter reading from that blood droplet. My nurse usually had to squeeze my skinny finger pretty hard to get a large enough drop onto the meter's test strip. Somehow, she managed to stick a large capillary just right and my blood spurted on her wrist, above her gloved hand. I thought it funny the way her face contorted. Even though the insulin syringes used tiny gauge needles, I still hated the injections. It was a cowardly mental thing—a needle is still a needle and getting poked is still getting poked.

Although, I wasn't a dream machine like Mom, I did have a doozie once in awhile. Lynn, my transplant coordinator told me a lot of post transplant patients had hallucinogenic dreams due to the powerful drugs they were on, which usually went away after the dosages were lessened. She wasn't kidding. I had, what could only be called, bad nightmares.

In one nightmare, I was a sultry prostitute living and working in a brothel out in the desert. I fell in love with a young monk from a neighboring monastery. We met secretly in nearby sand dunes where we played like laughing children. After I stole his virginity, we made plans to run away together to start a new life.

My boyfriend monk's abbot was an evil man who owned the brothel. All the monks living in the monastery had no idea he was anything other than a pious abbot. On the night before we were going to run away, the abbot came to my room and strangled me to death with his rosary. My monk boyfriend showed up and found the abbot standing over my dead body. The abbot confessed that he was a dealer in human organs, taking them from monks and prostitutes. Enraged with anger and grief, my monk boyfriend attacked the abbot. After a furious struggle he managed to kill the evil abbot by stabbing him in the temple with his cross.

In another nightmare, I became dinner for a half-human, half-spider who stung me with a paralyzing poison. I think these nightmares were hallucinogenic since they felt way too real. I never described them to anyone, not even Dad. I had no reason to do so.

Dad dedicated himself to my care and support, so much so that he was like an unpaid nurse's assistant. This freed my assigned nurses from having to come see me every time I needed some trivial thing done like having my bed adjusted. What a good daddy! He stuck with me like a strip of velcro. On my first attempt to get out of bed and stand up, he was there to catch me when my atrophied legs gave way. If not, I would have fallen, dragging my portly nurse with me, into a heap on the floor. Knowing he was there gave me a special feeling of security. He was a blanket of protection for me to snuggle under.

My days and nights consisted of a never-ending parade of interruptions making sleep next to impossible, not a good thing for a natural born insomniac. Swallowing handfuls of pills, getting injections, having vital signs checked, blood draws, x-rays and scans, echocardiograms, ultrasounds, biopsies—on and on it went, almost nonstop. There were some interruptions that I didn't mind. I loved the harp and guitar music played by visiting, volunteer musicians. Those were

bright spots in otherwise exasperating days. Playing games and watching movies on my laptop computer only strained my bloodshot eyes.

Once a week, a volunteer brought a therapy dog to visit the patients. I wasn't yet supposed to interact with animals, but for an animal lover like myself that was an unacceptable rule. My canine visitor was an immaculately groomed Border collie, a former show dog with big friendly eyes. "Come here boy," I said in my best coaxing tone. The female dog, nonplussed by my referring to it as a boy, began wagging her tail voraciously, beating up my IV pole. That tail was like a subtle weapon causing collateral damage to anything within wagging range. The dog stretched her head toward me and gave my face a saliva bath with her slurpy tongue. It was then that I remembered how doggy breath sometimes smells like that place under the tail where they often lick. My memories are filled with stupid little thoughts like this.

Most likely, my collie visitor thought I smelled, too. After all, I was not allowed to shower until my surgery wounds had healed. Water has bacteria swimming around in it, and who knows what other unfriendly microscopic bugs, patiently waited to invade my weakened body. Yeah, I know, what about that collie's tongue? I did have parts of my body sponge washed by a nurse's aide, which wasn't much relief from those vinyl-covered mattresses that tended to make me sweat passively.

When doctors and clinicians came to check on me or to do a procedure, it was always sudden and unexpected, usually right when my food tray arrived or when I just sat down on the toilet. "Sara, I need to take you for a CT scan" or "I need to draw some blood." I hated surprises that came at inopportune moments. It made my life seem too disorganized. I didn't mind when a cardiology resident showed up to clip away my surgical staples, knowing that once they were removed I could, at last, take a needed shower. I was flabbergasted when he only removed the staples from the top half of my surgical wound. The next day, a hepatology resident removed the bottom half staples. I never understood why one doctor didn't remove all the staples at the same time.

My first hot shower since arriving at PCMH was pure ecstasy. With the assistance of my nurse and her aide, my IV lines were temporarily disconnected and wrapped to repel the water. My walking around had strengthened my legs, which now supported me more easily. Once swollen from edema, my legs now looked boney and meatless. I was the perfect stick figure. Best of all, my matted hair was cut and combed out.

I knew my discharge day would not be far off. I no longer needed dialysis, my blood lab numbers were good and I had no more diet restrictions. I felt reborn in a physical sense, reanimated with life. I sensed my organ donor's soul had melded with mine into a kind of super soul. Barring any future complications, I was ready to face the world with a powerful spirit in spite of having a weak and broken, physical body.

30. SUPPORT GROUP

John Goodheart, the lead social worker at Pacific's Comprehensive Transplant Center, talked me into attending a meeting of his bi-weekly, support group for post transplant patients and those on the waiting list. Standing in the doorway to my room, he waited for Dad to help me get my slippers on before we all went together to the meeting room on the first floor. Too gregarious to be a priest and too sincere to be a preacher, he found his niche as a hospital social worker helping people deal with all the issues related to organ transplantation. It was a perfect match for a man of his moral character.

"Hey, you've got flowers out here," he said enthusiastically.

"Can't have them in my room. Not supposed to be exposed to pollen," I replied, shuffling my way out into the corridor with Dad pulling my IV pole behind me. I hated being tethered to that thing like I was some kind of bonefish at the end of a fishing line. I wore two hospital gowns, one in reverse, to hide my shrunken ass posterior.

There were only ten people in the room, four men and six women, all sitting in folding chairs along the walls facing each other. Dad and I sat next to John while everyone covertly stared at us out of curiosity. I was the only person not dressed in street clothes, marking me as an obvious inpatient. John asked for everyone's attention and introduced Dad and I to the group. His Adam's apple moved noticeably as he spoke, reminding me of an egret swallowing a squirming perch. Combining that image with a hairstyle combed in the shape of a colonial tricorner hat, he personified an image of Ichabod Crane.

As moderator, John, did his best to prevent those who talked too much about themselves from doing just that. He tried steering the subject matter toward learning about the transplant process for the benefit of those who were still on the waiting list. In addition to myself, one man and two women had already received gifts of life—a pair of lungs, kidneys and a heart. The group's interest in me sharpened when they learned I had received both a heart and a

liver. I didn't know what to think with all their varied reactions. One woman began to cry, another held her hands over her mouth, while others prayed or whispered, "Dear God." I felt awkward and confused, not knowing what to say or do. The last thing I wanted was to have a whole lot of attention focused on me.

John realized how uncomfortable I felt and began speaking in order to direct the group's interest away from me. "What I'd like for everyone to discuss today is how do we handle any problems that come up and how we deal with those bumps in the road?"

A chubby, middle-aged lady with a red face raised her hand. I surmised she needed a liver due to alcohol abuse. "Well," she said loudly, "I would like to know why it's so hard to find a parking place around here. I had to walk three blocks and barely got here in time."

"I'll find out who you need to talk to about that," John answered diplomatically. "Please, we need to focus more on medical issues."

The group grumbled, unhappy with the obese lady's wasting their time by bringing up something unrelated to the gist of the meeting. The man across the room from me rolled his eyes and frowned. I heard a woman say, "bitch" under her breath. Even Dad made a comment, loud enough for everyone to hear: "Exercise is good for you." I figured the lady had just as many fat cells in her brain as she did in her body.

A woman, who had her heart transplant six months earlier, spoke about how horrible it was when she became aware of what was going on near the end of her surgery while she was being stapled up. "I felt so much pain, I wanted to scream and writhe, but I couldn't move. I was paralyzed. I could hear talking. It was like burning in hell. I still can't get it out of my mind," She sobbed, knowing an experience like that could never be fully understood by anyone. It is very rare, but it does happen when an anesthesiologist under treats a patient.

John wrote furiously in his notepad. He seemed unnerved. He looked at the weeping woman and said, "I'm so sorry that happened. We live in an imperfect world and hospitals can sometimes be imperfect places. Still, it isn't fair, I know."

Everyone took turns describing specific problems they had to deal with. Several in the group declined to say anything at all. When it became my turn to speak, I folded my arms and froze, forcing Dad to speak on my behalf. I had planned to talk about Glenn and his odyssey, but decided this wasn't the right time and place to do that. Besides, talking in front of overly attentive strangers was too frightening. I don't know why I can be such a chickenshit, sometimes.

Dad gave the group a quick synopsis of my medical history then attempted to adhere to the theme about problems and how to handle them. He mentioned two examples. The first was about how a resident came into my room in the middle of the night and removed the jugular vein catheter from my neck because he believed it to be infectious. The next day, it turned out, he had done so without consulting my transplant physicians. Tests were negative for infection and I had to have a new cath put in before my next scheduled dialysis. The next time *anyone* I don't recognize attempts to do anything to me, I will adamantly refuse until I first consult with my transplant doctors. Problem handled by preventing it from happening in the first place.

The second problem I would have preferred not to have been mentioned. A tube that had been removed from a femoral vein in my groin left a wound that wouldn't stop leaking and, consequently, wouldn't heal. I was using dozens of thick gauze pads on a daily basis to absorb the fluid. When I used up my supply of pads, I substituted menstrual pads. The tissue fluid would often run down my leg, causing skin reddening and welts. It felt like I was being burned. The problem was resolved with sanitary napkins and surgical repair.

It seemed to me that the meeting was more of a complaint forum than a support and "crying towel" type of thing. Either way, I had no intention of attending anymore of John's support group meetings. I decided that my time would be better spent as an advocate for organ donation. When someone loses his or her life from sickness or from an accident, why should it be in vain? Multiple lives can be saved from a single organ donor. Personally, I think a donor's spirit continues on, melding with the spirit of the recipient. I can think of nothing nobler than giving the Gift of Life.

31. HISTORY LESSON

A few days after going to the support group meeting, John, the transplant social worker, came to my room. He appeared excited. "Sara, would you like to meet President Fordham? He's here right now, getting a check up."

"Who is he?" I asked puzzled. Dad and John seemed surprised by my ignorance, forgetting about all the school I had missed. History and Government were not subjects I had learned much about. In fact, I hardly knew anything about who was who in the present, except for doctors.

Dad explained, "Fordham was president before you were born so, of course, you wouldn't know who he is."

John interjected, "He's pretty old now, in his eighties, but his mind is still sharp. He has a remarkable acumen about people and politics."

"What's that mean?" I asked. I hated it when new, unfamiliar words were thrown at me.

"He's got a keen insight about people, an ability to judge people," Dad explained. "You know, the kind of person you can't fool."

"Oh. Why would he want to meet me, anyway?" I gave Dad an inquisitive look.

John answered my question. His head bobbed on his long neck as he spoke. "One of the staff must have mentioned you to him. I'm sure he's interested in seeing how you're doing. If you're ready, we can go right now."

"Okay, I'm ready," I said, as if it wasn't a big deal. Obviously, it was for Dad and John. "What do I say?"

Dad told me not to worry about it. The conversation would be like a dance, all I had to do was follow his lead. With mutual respect there will be no trouble bridging the generation gap. Ask questions and answer questions, that's all I had to do.

We took a service elevator to the top floor and made our way down a corridor toward President Fordham's room. A secret service agent met us at the nurse's station and escorted us to his room. The agent told us to wait while he entered the room. He came back out and instructed me to go in while he stayed outside with Dad and John. I was having a private meeting (or was it an audience?) with a former president. How cool is that?

Not having any clue about things like etiquette or protocol, I slowly sauntered in, hesitating like a cat every few steps. Fordham sat in a chair next to his bed wearing a blue robe over grey hospital scrubs. A presidential seal adorned the robe's pocket. In spite of his advanced age, thinned out, white hair and mottled skin, he personified elegance. Now, I understood what distinguished looked like. It was a quality that followed greatness, not the other way around.

"Hi," I said softly. I worried he may not have heard me. He did.

Fordham stood up, greeting me with a big hug as if he were my grandfather. "Sara, it's a pleasure to meet you."

"Thank you, sir. I'm honored to meet you." Thankfully, I remembered to be respectful.

"Please, no formalities, my dear. Call me Robert. Now tell me how are you doing."

"Fine, I guess. Better than anyone expected."

“That’s wonderful. I admire your courage and attitude very much.”

“I don’t think I’m so courageous,” I confessed.

“Well I do, young lady. From what I’ve heard, you are darn special.”

I felt embarrassed by his compliments. I asked why he was there, if he was okay. He told me he had to come in for a “senior citizen’s” check up twice a year, because it was better to be proactive instead of reactive when it came to matters of health. I wanted to get his perspective and find out what he thought about some of the things that bothered me about our crazy world, like terrorism.

“Mr. Presi..., er, Robert, Why do the terrorists hate us so much that they could kill all those innocent people in those buildings in New York—that 9/11 thing?”

“It’s human nature to hate, but when hate reaches a level that’s unconscionable and goes beyond the tenets of the perpetrators own religious beliefs, including suicide to carry out a premeditated, terrorist attack against innocent people, then it’s madness and an affront against God. No matter what your faith, there’s no justification for it.”

I wasn’t able to digest all that Fordham said, but I did understand the gist of it. From my teenage girl’s point of view, I figured there must be some kind of brain washing or mind control going on to program someone’s mind to be able to commit despicable acts and pretend it is God’s will. It is tantamount to saying God is evil instead of good. If God is mercy and love then the terrorists cannot be anything other than evil and despised by God. If you believe in God, no matter what your religion, then the logic behind justifying terrorism is flawed.

“Robert, what is the hardest part about being president?” I felt uncomfortable calling him Robert. I wished I could call him granddad. I wanted him to be my grandfather. Remove his shield of power and he was a down-to-earth, caring man.

“Controversy, inescapable controversy. It’s a damned if you do and damned if you don’t kind of life. Don’t misunderstand, Sara. It’s a great job and a great honor to be president. Getting to know so many world leaders and other important people is awesome. I have to admit, sometimes politics is a hard to tame beast, but if you can, it’ll take you on a wild ride.”

“Politics seems too mean and cutthroat to me. I don’t see how you can win without being dishonest. It almost invites corruption.”

Fordham chuckled. “Are you saying I’m corrupt, Sara?”

“No, no. I mean...you aren’t, are you?” I began to squirm, feeling my cheeks get warm.

“First, let me say everyone lies at different degrees. Often, we have no choice. Maybe there’s no other way to get a job without fabricating some fact on a job application. It can be a matter of survival. The key is whether or not you have evil intent or not, for example, being dishonest in order to break the law. Sometimes truth is only a point of view. One person’s lie may be another’s truth.”

I noticed Fordham’s eyelids drooping and decided he needed me to go so he could rest. I told him I felt nauseous (I lied) and needed to return to my room. We exchanged cordial hugs and he presented me with an autographed book about his years as president. Meeting and talking with a former president and political icon was an honor, a history lesson in the present time.

32. GOING HOME

After seven weeks, I had healed extremely well. My kidneys were working normally again, my blood sugar levels were fine, and I was walking around on my own looking for ways to prevent hospital boredom from setting in. Once off my floor, I enjoyed blissful anonymity. I explored and visited every department from the ER to the nursery, no longer having to pull around that unstable, top-heavy IV pole. I thought it dumb that they didn’t have larger wheels on those things. I was unshackled, free to roam at will. I still had IV’s in both of my arms, which would not be pulled out of my veins until my last day at PCMH.

Doctor Akumin found me in my room waiting for my dinner tray to arrive. He knew I would be there during that time since I would never miss a meal if I could help it. He noticed Dad had supplemented my bland hospital food with a tostada covered with refried beans and shredded cheese, along with an extra large burrito. Dad was munching on the last of the six tacos he had brought for himself. The appetizing odor of a Mexican restaurant permeated my room. I thought I detected a deep growling sound coming from the direction of the good doctor’s stomach.

“Sara, would you like to go home? Dr. Akumin asked, sliding his cold stethoscope off my chest.

“Yeah!” I shouted happily. “Can you get the nurse to take out my IV’s so I can get dressed?”

“Hold on young lady,” he said. “Not until tomorrow. We still need to put together your instructions, appointment schedules and give you your first month’s supply of medications. Oh, our public relations people will want to take some pictures of all of us.”

Doctor Akumin shook hands with Dad and gave me a big bear hug. This time I definitely heard his tummy growl and I offered him my burrito. Realizing I had heard his rumbling stomach, he replied unembarrassed, "Thank you, Sara. I've got a big ol' pizza waiting for me already."

I didn't know if he really had a pizza waiting or if he just said that as an excuse not to take my burrito. I knew his taste buds had to have been activated. Someone once told me that hunger is like sex; once it takes hold of you it doesn't easily go away until you satisfy the craving. I don't know about that comparison. I'm still a virgin, although I regret not getting it on with Mark. I was always too afraid he would die on me, gasping for oxygen.

My mind was a tightly wound, clock spring with going home dominating my thoughts. I couldn't sleep that night and needed to take a couple of sleeping pills. I had a standing order for them in my chart because of my insomnia. The pills finally calmed my restless mind and I fell asleep. The last thing I remembered was hearing Dad snoring away like a car motor without a muffler. Somehow, he managed to sleep on one of those folding beds with those thin mattresses. His feet stuck out over the end, getting in the way of the night nurses whenever they came in to check my vital signs. I imagined his annoyance at being awakened by a cellulite-loaded thigh brushing against his toes.

A dream began to dance around in my mind aching for a meaning, but I did not understand it. Can dreams really ever be interpreted, I wondered? An angel in a wispy, white dress with waist length, platinum hair and fiery wings appeared. She had a face like Jane's with piercing, translucent eyes. I stared, transfixed, into her mesmerizing yet nebulous eyes. What kind of angel was she, I wondered? A Valkyrie? A Phoenix? A Seraph? A product of my restless, overactive imagination enhanced by immunosuppressant drugs? Even though her eyes were captivating, her facial expression remained stoical, providing no clue as to whether she was a good or bad omen. My nurse woke me up for my morning pill-swallowing routine and unlike most dreams that are instantly forgotten, the image of my "angel" was vividly imprinted into my mind. It would be up to me to decide if my vision meant something good or something bad. In case my own positive or negative thinking might influence my destiny (and life), I convinced myself that my dream represented a wonderful new rebirth for my physical self. I also crossed my fingers. Nothing wrong with a superstitious gesture I decided.

After I finished chomping down breakfast, my IV's were removed and I put on the new clothes Mom had bought me. Since Mom wasn't too fashion conscious, the clothes weren't exactly color coordinated. A pink blouse with its

old-fashioned lace collar clashed with the forest green shorts, making me look nerdier than a nerd. Damn it, Mom, what's with you? At least the shorts allowed me to show off my new meatless legs. My transplant coordinator, Lynn, gave me a folder with my follow up instructions and a utility bag full of my first month's medications.

I walked out of my room with Mom and Dad for the last time. I had become so accustomed to living in that room, I felt like an animal leaving the safe haven of its den. Going home at last boosted my spirits and I couldn't stop smiling. Good thing, too, with a large crowd waiting for me. I was some kind of medical celebrity, I guess, posing with my transplant doctors for pictures and speaking in sound bites into several TV reporter microphones.

"Sara, what do you have to do differently to take care of yourself?" The TV people were bumping into each other to hear my soft-spoken reply.

"Well, I have to watch what I eat and drink. No heavy lifting, no cleaning bird cages, fish tanks or cat litter." I looked at Dad knowing he had inherited those chores. I also knew the fish tank would soon disappear from our house. I jokingly continued, "I don't drink, smoke, have sex, or take illegal drugs—got my own supply of legal drugs now."

An amused reporter asked, "Sara, do you consider yourself lucky to be a survivor?"

"Yes," I answered emphatically, "It's my doctors who made the luck. They say fortune favors the bold and these guys were the only ones who would transplant me."

"What's the first thing you're going to do when you get home?" Another reporter asked.

That was a reasonable question I didn't mind answering. "Hug my kitty, Luna."

"What else?"

"Go see a movie and go to a seafood restaurant," I replied enthusiastically, looking at Dr. Akumin. "But no shell fish. Not allowed to eat that."

There were lots of tearful goodbyes and hugs with the caring Pacific nurses and doctors. Even though I could walk, hospital protocol made discharged patients ride to the exit in a wheelchair. Off I went with a nurse pushing me away from all the happy, waving people.

The last question a TV reporter asked me, right after an expected one about how I felt with a new heart and liver, was: "Anything you'd like to tell our viewers?"

My mind underwent a brain fart and went blank. “Oh no,” I thought. The question was too open-ended. “What do I say? How do I answer? Holy crap, I don’t know.” In a panic mode, I did what any fool like me would do. I tried to pull an answer out of my ass. I didn’t have to.

“Words can never express the gratitude I feel for receiving the gift of life. Two gifts of life, actually, a heart and a liver,” I replied in all sincerity. “Never give up, think positive and keep the faith!”

Fool or not, I meant what I said with all my new heart.

33. CELEBRATION

A month after my hospital discharge, I found myself airborne once again in a G4 high over the desert. From the cabin window I watched a pair of dust devils crossing a dry lakebed, their cyclonic winds ripping away all the loose sand granules from the surface. Mom, Dad, Tommy and I were with Jane and Susie heading to the Windfall Hotel and Casino in Las Vegas to celebrate my successful double transplant. Ironically, we had all just finished a conversation about how smooth the flight was when we felt the plane shudder and bounce. The unexpected air turbulence knocked over our wine glasses, spilling the fermented grape juice into our laps, garnished with tortilla chips from a flipped over bowl.

Mom closed her eyes and began praying. Dad and I blurted out, “Holy shit!” simultaneously. Tommy froze rigid in his seat. Jane and Susie grabbed hold of each other, panic stricken. I looked out my window to see if the wings were still attached to the fuselage. I didn’t want to die in an airplane plummeting toward the earth, exploding into a fireball. It’s too violent, too dramatic. I prefer to pass away peacefully in my sleep, thank you. At 500 miles per hour, the G4 exited the turbulence within seconds after entering it. We kept our seatbelts buckled on for the remainder of the flight.

We arrived on a Saturday morning at the extremely crowded Windfall. The celebratory dinner in my honor would begin at six that evening, giving Tommy and I plenty of time to lose our money playing the casino’s slot machines. Jane had set up everything in advance, including having the hotel send out the formal invitations to keep her anonymity intact. I had no inkling that this would be anything more than just a fancy dinner, no different than the last time we were in Las Vegas. I loved eating in restaurants for two reasons: The food always tastes better when someone else prepares it and you never have to wash any dishes. My idea of doing the dishes at home is taking empty pizza boxes to the trashcan.

A few minutes after six, Tommy guided me past the entrance to the Windfall's seafood restaurant to an open door next to a tripod-mounted sign proclaiming, "Reserved – Sara Jones Banquet." I was astounded at seeing so many familiar faces, all of them smiling at me as I followed Tommy to a table next to a dais, where my parents waited for me with Jane and Susie. Bewildered at first, I quickly realized what was happening. I would have unabated celebrity status for the evening, whether I liked it or not. If there was ever a time when I needed multiple cocktails as a crutch for emotional support, this was it.

While waiting for my entrée, I nibbled on hors d'oeuvres and watched a magician perform his repertoire of tricks. Thankfully, he used no rabbits or doves in his act. Bunny pellets and bird poop would be harmful to my less than normal immune system, not to mention being a contaminant to my steak and lobster dinner. A couple of clowns visited the guest tables, gyrating around like lobotomized monkeys. I never really liked clown acts, even as a child. Clowns were way too silly to make me laugh. They just behaved very much like, well, clowns. I was glad everyone else found them entertaining though, and they did add color to the mood of the evening.

A man in a black suit with a red tie began to speak from the dais, close enough for me to pull on his pant leg. "Hello everyone. May I have your attention please? My name is Rocky Marroni. I'm the Director of Public Relations for the Windfall Hotel and Casino. It's my pleasure to welcome you here this evening to honor a very special young lady. Sara Jones!"

Oh, no! He pointed his stubby finger at me. People were clapping. "How do I hide my blushing face? Use your hands, idiot!" I thought to myself.

A new speaker patted my shoulder as he passed by me to the dais. It was Dr. Akumin. It was the first time I saw him not wearing a white lab coat. His dark jacket and white shirt reasserted my vision of him as a giant Panda. I wondered if the appetizers on his table were bamboo shoots.

Dr. Akumin introduced himself and began to do what I feared, talk about me. He summarized my medical history in layman's terms, paused briefly and continued, "We all know how brave Sara is, her fighting spirit, her wonderful attitude and her modesty, but she is much more. She represents everything positive about transplantation and inspires us all with her million-dollar smile. I know she wants me to stop speaking about her so I'll end my remarks with a question. 'Sara, my dear, how can you be such a trouper and be so sweet at the same time?'"

Applause followed Dr. Akumin as he made his way back to his table. I worried that there might be plans to make me into a poster girl or have me give speeches advocating organ donation. I have already done a lot TV interviews about the importance of donating life, but I would be scared shitless talking in front of groups of strangers. These thoughts left my mind as I studied someone new at the dais. A short, rotund man with a pointy baldhead looked around at the guests with a mischievous grin.

“With all the MD’s and RN’s from different hospitals in here, it looks like a medical convention. How many of you, besides Sara, plan to get wasted and end up spending all night in the casino?” he asked. Hands shot up around the room along with shouts of merriment.

The bald man pointed at one of the tables in the back of the room. “Who the hell are you guys? Why are you here? Are you lost?”

“We’re Sara’s nurses from Oakden,” my SPU buddies shouted back.

The man walked around from table to table, chiding everyone and cracking jokes, until he came up behind me. I wanted to turn and hiss like a cat at him for invading my space. “Ladies and gentleman, I give you the beautiful Sara Jones,” he said, clapping his fat hands inches away from the back of my head.

My new heart was thumping wildly in my chest. I was stuck. Now, I *had* to get up and talk to a room full of people with piercing eyes. I reminded myself that these were not strangers, just empathetic friends and if I melted into a pile of body parts or lost my voice, they would not behave like sympathy mongers. They would simply understand. It wouldn’t be a big deal. I needed to get my little speech done and over with before dinner was served. I didn’t want any bits of food stuck between my teeth. “Do it, fool!” I told myself and stood up.

“Hi,” I said rather sheepishly at first. Dad gave me a subtle nod of approval and my nervousness began to fade away. “I’m not sure what to say, except thank you everyone for helping me stay alive. I don’t think I’m special. I don’t think I deserve all this attention either. I do hope to find out about the person who donated their heart and liver to me and meet his or her family. You know, it’s impossible to say in words how grateful I feel. Damn it, I love you guys!”

Out of impulse, I went to every table and hugged all my friends, one by one. I unashamedly cried with happiness until my tear ducts literally went dry.

34. REVELATION

After the banquet, everyone broke up and headed in different directions. The majority traipsed off looking for slot machines and blackjack tables, or an empty seat at one of the people-infested bars. The smarter folks went to their rooms to sleep off the effects of alcohol overindulgence. I ended up with Susie in a limo, casino hopping. She wanted me to experience Las Vegas beyond the Windfall, which I didn't mind, even though I figured there couldn't be a whole lot of difference between one casino and another, except for the fabulous variety of shows put on by big name, star performers. Besides, she was really fun to hang out with and I loved looking out of the limo at all the neon lights that glittered everywhere we went. It felt like traveling through the middle of a fireworks display, where the flashing lights seemed to hypnotically beckon you. Satan, himself, couldn't do a better job enticing people into hell. Casinos are a far cry from hell, though.

Either from too much wine, the motion of the car, or from medication side effects, I abruptly felt a wave of nausea. "Pull over," I gasped. "I gotta vomit!"

Susie yelled at the driver to stop the limo. After cutting off an SUV in the lane next to us, we came to a tire-screaming stop against the curb. Susie helped me scramble out as the driver ran up to assist. My face turned red and I puked out half my dinner onto the sidewalk. The pedestrians walking by had disgusted looks on their faces. I wanted to tell them that this was not a vomitless society we lived in, but I was busy catching my breath. One woman appropriately uttered, "Ewwwww!"

"Vino veritas," Susie said loudly.

"What's that mean?" I asked.

"Truth in wine," she replied philosophically.

In a few minutes, we were back in the limo and I swished away the taste of bile from my mouth with a fresh swig of chardonnay. I remembered throwing up the last time I was in Las Vegas. It was something I seemed to be good at. Susie decided that we should return to the Windfall and call it a night. I agreed, not wanting to push myself any further past the boundaries of common sense than I already did. No longer feeling the childish need to have fun, I decided to query Susie about Jane. I couldn't help but wonder why she took such an interest in me, why she avoided talking about herself, and why the anonymity?

"Susie, can I ask you something?"

"Sure," she replied sensing my seriousness.

“Why does Jane do so much for me? The trip to Florida, this banquet, and why can’t I tell anyone about her? I wanted to thank her during the dinner, but wasn’t supposed to. I feel bad that she gets no recognition, no praise, when she is the one who deserves it more than anyone else.”

“Sara, I think you should know something about Jane, but promise me to keep what I tell you to yourself. It would be awful if you betrayed my trust. I have mixed feelings about telling you, because I’ll be betraying Jane’s trust in me. I’m going to do it, only because I think Jane is wrong for not telling you.”

“Okay,” I said. Goose bumps prickled on my skin in anticipation of being hit over the head with some secret information. I looked to see if the privacy glass between the driver and us was closed. It was. I listened intently to Susie, cold sober, as if all the alcohol in my body had mysteriously evaporated away.

“Jane has been through a lot personal tragedies. Her husband made a fortune in the computer software business. He was sort of a geek, but he was a very good husband. He died from colon cancer about ten years ago. Jane was devastated. They had a son, Zack, a very bright kid, and Jane poured her love on him. He became the one and only man in her life. Several years ago, before we went to Florida together, Zack was diving into their pool and hit his head on the edge. It happened right in front of Jane. Lots of blood in the water. It was so awful. I saw it, too.”

Susie began weeping and paused. I fell into a semi-state of shock. She regained her composure and continued.

“Anyway, Zack ended up in a coma and on life support until he died on January 30, one day before your transplants.” Susie put her arm around me. “Sara, your heart and liver came from Zack. Jane’s son is your donor.”

“Why doesn’t Jane want me to know?” I asked. Tears began welling up in my eyes.

“Sara, not every transplant donor or recipient wants to establish contact. Some do and some don’t. It’s a very emotional and personal thing and we have to respect that. Jane is dealing with the loss of a husband and a son. I think she sees in you the continuation of Zack’s spirit and is afraid she would mentally collapse if something happened to you. You are very special to her *and* to me, too. Please, now that you know, don’t behave differently around her. Give her time, maybe in a year or two she will want you to know. In fact, I’m sure she will.”

I was at a loss for words, in fact, I was at a loss for thinking. All I could do was hold on to Susie to keep myself from flipping out. We hung on to each other until we arrived back at the Windfall. When the driver opened the door for us, we

stayed in the limo for ten minutes, gathering our composure. No doubt our demeanor created a gay couple “fight and makeup” scenario, much to our chagrin. Luckily, a Las Vegas chauffeur tends to see or hear nothing, especially when given a decent tip.

I went straight to my room, swallowed my pills, showered and fell across the bed without going under the covers. I thought about how transplant recipients can sometimes take on certain characteristics from an organ donor. I had no idea if that was true or not, but if any of Zack’s traits manifested in me, I hoped they would be good ones. I needed to find out all I could about him.

That night I had a strange dream. I was on an endless beach, wading in the surf with Mark who was no longer sick, talking about love and marriage. From out of the ocean surf, Zack appeared. When the waves knocked him down, he would get up again, getting closer and closer, until he reached us. We put our hands on each other’s shoulders forming a spiritual triad. In the morning, I crawled out of bed with a smile on my face. It mattered not whether my enlightenment was only from a dream.

35. SIDE EFFECTS

Zack’s heart and liver kept me among the living for the first, post-transplant year without any rejection episodes. My first annual biopsy to check for signs of organ rejection turned out negative, which meant I wouldn’t need another biopsy for a full year, barring any unforeseen complications. During the initial, post-transplant year, I underwent frequent biopsies, which were done in conjunction with heart catheterizations. They always went in through my neck, an uncomfortable, invasive procedure that I dreaded. Luckily, Dr. Akumin finally ordered my medication dosages cut back, lessening the side effects that were messing up my drug-saturated brain, causing intermittent lapses of concentration, frequent mood swings and hallucinations. Not a good thing for anyone near me to have to put up with.

During the first half of 2007, my body handled the massive doses of drugs fairly well and I was able to live a close to normal life. I went on a cross-country, road trip with Mom and Dad to see and learn about the country I lived in and visit several national parks. I was still caught up in the media radar, doing occasional interviews about the need for organ donation. A national magazine assigned a writer to do a story about my life in general and my trip in particular, entitled, “Journey of a New Life.” That seemed to me a bit too much. However, I did feel

like I had experienced a new life when I gazed at the geographical wonders of places like Yellowstone and Yosemite. For a bona fide, planet-lover like me, it was awe-inspiring and wondrous. I felt a spiritual affinity with all the wildlife roaming free in the mountains, on the plains, and in the forests. I was as much a part of them as they were of me. As I touched the weathered side of a rocky outcrop on the edge of the Grand Canyon, where I had once stood before I had my transplants, I knew that one day I would become as dust on the earth, yet my soul, along with Zack's, would become part of all that was still alive within our world's magnificent biosphere.

While on a public relations, B-roll shoot for PCMH, where I interacted with various animals at the Oakden Zoo, I experienced an unexpected hallucination lasting for several seconds. A young, bulbous-eyed giraffe I was feeding with an oversized, baby bottle transformed itself into a long-necked dragon about to swallow my entire arm. I dropped the bottle, splattering milk all over the video cameraman's sneakers. I'm sure the youthful giraffe considered me an all-too-human jerk for depriving it out of all that vitamin-enriched milk. The cameraman wasn't fazed at all, as if he saw baby bottles dropped from giraffe mouths every day. I suppose his sneakers were way too cheap for him to be concerned about.

More worrisome and dangerous, were the losses in my concentration that lasted anywhere from a few seconds to several minutes. Dad almost jumped out of his skin, screaming for me to stop, as I blank-mindedly drove our car through an intersection without stopping for the red light. It would have been a horrible tragedy if someone had been killed or maimed. On another day, I drove right through a stop sign. I immediately pulled over to the side of the road, my bones shaking enough to become separated from my flesh. I realized it wasn't safe to drive and I wisely stopped doing so out of fear. Brain farts like these affected everything I tried to do, from reading to brushing my hair. Dyslexia and short-term memory loss were another aggravation.

I considered the immunosuppressant drug side effects an irritating inconvenience that I would get over once my dosages were significantly decreased. As long as I didn't do anything stupid like drive a car or ride a motorcycle, I wouldn't bother anyone else with these personal problems. My uncontrollable mood swings were something else again. That *did* bother everyone. At times, I became two different people, like some kind of a Jekyll and Hyde, schizoid girl. I felt as if I had a case of fecal encephalopathy; that is, shit for brains. This alter ego was not part of my spiritual self. It was a separate, drug induced, mental parasite thing clinging to the fringes of my mind that made me

feel sorry for myself, complain too much and become argumentative. There were many sunny days where I was my normal self, but when the bouts of negativity set in, my days became stormy ones.

Before Dad realized what was going on with me, he thought I had postmenstrual syndrome. Mom clued him in that PSP wasn't possible since I had amenorrhea. I haven't had a period for the last three years—something to do with my hormone imbalance. I will never know how he withstood my litany of verbal discontentment and abuse. There must be truth in that old adage, "love conquers all." There is a fine line between many things, including love and hate, and I often tread on it like a tightrope walker without much balance.

"I can't be strong like it's expected of me all the time!" I wailed tearfully at Dad. "I'm tired of all the hurting. I'm always told that things will get better and they're not. I don't think it's going to happen—ever! I was born defective. Nature would not have let me live. Why do I have to be so brave?"

"Sweetheart," Dad said unflustered. "It's okay. Let your feelings out. I know it's hard waiting. Hang in there. I promise you everything will get better, really."

As if an invisible, mood switch had been thrown, I calmed down, grabbed Dad and held him tightly. "Daddy, what's wrong with me? I hate being like this."

"Just recognizing something's making you upset is a good sign. It's just the medicine, that's all."

For the time being, I reverted back to semi-normalcy. Still, any trivial event might set me off. My mind somehow magnified things out of proportion. A ticking clock would become tantamount to a beating drum. A needle poke would feel like being stabbed with a samurai sword. Hypersensitivity was just another word for *leave me alone*.

I was slowly weaned off my high drug dosages and I just as slowly reverted back to my old, "lovable" self. Before the transplants, my doctors told me I would need a strong family support system. They weren't kidding. Dad was my main supporter and crutch, Mom my sympathizer, Tommy my distracter, Luna my purring comforter, and myself, an alternating pain in the ass.

With my twenty-first birthday looming, along with the last month of the year, I planned on one final, personal victory, getting off my pain meds. I hoped that the withdrawal symptoms would be less traumatic than my immunosuppressant drug side effects, where, on occasion, I even thought about killing myself to find some peace. I chickened out, though. What I don't like about death is that you can't have fun anymore. It's totally boring.

36. INTERVIEW

Randall Skald asked a lot of questions and took lots of notes. He was a staff writer assigned by a large circulation magazine to interview me and come up with an inspirational, human-interest story about receiving the gift of life, namely transplanted organs. I agreed to the interview since the publicity would bring more public awareness about the need for organ donation, which meant more lives like Mark's could be saved. I wasn't quite sure why I was chosen to have my story told on this scale rather than someone else more deserving and courageous who had also survived against all odds. "Why me?" I asked, wondering.

Randall had just sat down on the sofa being careful not to disturb Luna who stretched out her front paws, exposing her claws and yawning in boredom. He leaned his bulky, well-nourished body forward and looked at me with friendly eyes. He was careful to avoid turning the interview into an interrogation and interspersed his questions with small talk as if we were friends casually chatting about the weather.

Before he began asking me his questions, he replied to mine. "Sara, a lot of why we want to do a story about you is because of your attitude. In spite of all you have endured, you keep bouncing back. You always have a smile on your face. You really *are* an inspiration."

"Thank you, if you say so." I replied sheepishly, knowing I didn't always wear a happy expression. While looking at him, a big smile involuntarily plastered itself across my face. Damn it. I couldn't help it. I always beamed at handsome guys, even middle-aged ones.

"I'm going to do this in two parts," Randall explained. "Today, I'll ask about your life before, during and after your transplants, and tomorrow I'll focus on your trip around the country. But it's all about who you are—your essence, so to speak—what makes you tick?"

Randall ran his hand through his thinning hairline and grinned back at me. His arms were hairy and I imagined his chest and legs were also hairy, like an ape. He placed a pocket-sized tape recorder on the coffee table between us. Luna immediately investigated the strange object with her sniffing nose to make sure it wasn't alive. If that cat could talk, she would have said, "All this because of Sara's smile? She can't even purr."

"Okay, Sara, first question. How did it make you feel when you were first told you needed a new heart and liver to survive?"

“Disbelief, then fear. I started crying. Everybody was crying. The thought of having someone else’s organs in me repulsed me at first. It seemed so unnatural. Something like, I wouldn’t be me anymore. Then a priest told me to think about my spirit instead of my physical body and I realized it would be okay. Something like that.”

“I understand Mammoth and other transplant centers turned you down. How did that make you feel?”

“I was totally pissed. Mammoth wasted more than half a year of my life for nothing. They gave me hope then condemned me. They shouldn’t have gotten my hopes up if they were only using me to experiment on.” I began to seethe. It was a negative experience better forgotten.

Randall seemed sorry and continued, “Pacific Coast Memorial accepted you as a transplant candidate and placed you on their list. I’m sure that must have been a great relief. How long did you wait before you got the call?”

“One year and two months,” I replied tersely.

“Okay. What did you do during the wait? How did you hold up?”

“I spent most of the time with my boyfriend in between my taps. He was on the waiting list for new lungs, but he died. It happened at Oakden Hospital while my Dad was there for G.I. surgery.” I didn’t want to talk about this period in my life and became sullen. Randall seemed to understand and quickly went on to the next question. I watched Luna walk out of the living room and head for the kitchen. She had an air of indignation about her.

“Sara, how did you react when the call finally came?”

“I was asleep. My Dad shook me awake. I went from a real cool dream being with dolphins to being bitten by reality. I was scared shitless. I was halfway to the hospital before I settled down.”

Randall was quite interested and queried me about how my seeing the moon influenced me spiritually and the calming effect it had on me. He then looked over his notes. “Sara, you have an affinity with animals. Can you give me some examples?”

I thought for a minute before replying. “I think it’s because animals can sense your feelings in different ways, depending on the animal. If you’re around a predator the worst thing you can do is show fear either by running away or just because you smell afraid. That automatically classifies you as prey. Obviously, if the predator is injured or starving all bets are off and you’d be in big trouble.” I laughed and continued, “I wouldn’t mess around with big animals that have claws and fangs.”

“How about the not-so-dangerous kind of animals,” Randall asked, looking for a more definitive answer to his question.

I told him about my experiences with all the animals I had interacted with, everything from birds to reptiles. My favorite experience was with a giant, Asian praying mantis. The insect actually recognized me and always wanted to cling to my face. It was as large as my nose. As it shed its skin and grew, I began hand feeding it fruit flies until it could handle large crickets. I named it Zorak.

“Okay, one more animal question. What are your favorite and least favorite animals and why?”

“My favorite animals are dolphins, orcas—well, all cetaceans actually. I love *all* cats, especially snow leopards and cheetahs. And all the raptor birds like eagles, hawks and falcons. Why? Because these animals are intelligent, beautiful, magnificent. Nature at her best. My least favorite animals are simians—gorillas, chimps and monkeys. I guess it’s because they are so much like us.”

“Sara, speaking of likes and dislikes, what do you like the most, besides animals, and what do you dislike.”

“I like art, music, movies, junk food, friendly people. I hate hypocrisy, dogmatism, dishonesty, violence.”

“Okay, I’m sure you’ve been asked this a lot. Who is your anonymous, mystery friend? The one who took you to Florida?”

“Sorry, can’t answer that.” I was a little perturbed since everyone in the media kept wanting to find out.

Randall shrugged his shoulders. “I guess no one will ever know. Let’s finish up for today with one last question. Do you know who your organ donor was? Any contact?”

I wasn’t prepared for this question at all. Since Susie told me, I knew, but I wasn’t supposed to know. I ended up doing something I abhorred. I lied my ass off. “I don’t know,” I said, “I wish I did. I tried to find out but apparently my donor’s family doesn’t want to make any contact. I understand and respect that. Maybe, it would bring out too many emotions. I guess it would make it too hard to forget and move on. I don’t know.”

“Thank you for your honesty,” Randall said. I felt like a complete ass. “Oh, I almost forgot, last question. I think you’ll like to answer this one. Next week we need to set up a day, or if you’re tired we can split it into two days, to do a photo shoot with our photographer. Where would you like to do the shoot—at the zoo, on a horseback ride...?”

“Horseback ride!” I interrupted with enthusiasm.

37. PHOTO OP

On the second interview day with Randall, I was groggy from not being able to sleep during the night. I purposely didn't take my sleep medication since I sometimes rebelled against needing to take so damn many pills every day. Some were critical to prevent organ rejection and I had no choice about taking them, but if I could skip swallowing several others, I did. One cabinet in the kitchen was dedicated to hold all my pill bottles and it resembled a pharmacy. It gets tiring having to gulp down over a dozen capsules every morning and evening. The smaller tablets kept getting stuck between my gums and tongue where they would dissolve, coating my palate with a very unpleasant, bitter taste. I choked on the larger, over-sized pills, struggling to get past my uvula, which acted like a sentry protecting my diminutive throat. If I tried to cut them in half they would crumble to powder. I wondered if I was the only pill popper who griped like an immature brat.

"Good morning Sara," Randall said cheerfully. I could tell he had a good night's sleep.

"Morning," I answered with envy. Mom brought Randall coffee and hot chocolate for me. Luna tried to snatch the floating marshmallow from my cup, meowing in protest when I pushed her away. This was as tough a life as she ever knew.

Randall's cheerfulness melted away into a more serious state. "Sara, I need to wrap everything up today. My editor is in a little bind and needs me back tomorrow. The photographer is having scheduling problems, but can do the shoot this afternoon. If you're okay with it, I need to call back the photographer and the riding stable."

"Sure, no problem," I said, suddenly wide-awake.

When it came to riding horses, now was always better than later. Randall got on his cell phone and coordinated the photo shoot for that afternoon. The riding stable was only an hour away. Dad queried me about why so many young girls liked horseback riding so much. I told him I didn't know the answer, but personally, it made me feel stronger, like a power trip. Riding on the back of a galloping horse is an unexplainable thrill that seemed to nourish my soul with energy.

Randall spent an hour asking me questions about my cross-country road trip before we all left for the riding stable. Where I went and what I saw didn't

interest him. How I reacted and felt did. He already talked with Dad and knew that stuff already. He switched on his recorder.

“Sara, What did you think when you saw how different other parts of the country looked like?”

“You know what? Our country is so beautiful. I mean I was awestruck. The Rocky Mountains covered with snow reflecting the morning sunlight. The forest-covered Appalachians with wind-blown fog moving fast through the valleys. Grassy plains as far as the eye can see. My God, how it must have looked in the past with vast herds of bison. All the different kinds of forests, Redwoods, Maples, Oaks, Pines...all the deer, bears, birds, everywhere. Wide rivers, fast-moving streams, lakes as small as puddles and as large as seas, filled with fish.”

“Whoa Sara, slow down. I get the picture. But how did seeing all this varied geography make you feel?”

“I cried. I guess I’m a sentimental nature-child. How can we be so blessed with all this incredible beauty and not try to respect it, to take care of it? I mean, it’s our home and we’re ravaging the land. We’re killing ourselves in the process. It makes me ashamed to be part of the human race when we’re so irresponsible with the very ground we walk on. What’s wrong with us? Why are we so destructive?”

I was getting visibly upset. I needed to get away from the subject I unintentionally steered myself into. Randall checked his recorder and asked a different question. We were approaching the stables.

“Sara, of all the places you visited, which one did you like the most?”

I took a deep breath, regaining my composure. “I can’t really say I liked one place more than any other when everything I saw had its own uniqueness and beauty. There were two places that affected me spiritually though. One was in a cave in the Smokey Mountains. To be deep inside the earth with all the strange rock formations with the utter silence made me feel like I really was a part of the earth. It was surreal. The other place was the Devil’s Tower. I couldn’t stop staring up at it. It was something special that the earth made eons ago. It was more than just a geological formation. I understood why the indigenous people felt the way they did. It was a massive, magical icon created by the earth itself.”

Randall drove off the paved highway onto a gravel road that led to the stable. Dad sat quietly in the back mentally digesting everything I said and how I said it. The photographer was already waiting for us along with the lady who owned the stable. She looked so cool in her western style shirt with tight jeans

tucked into her boots and a cowboy hat with an eagle feather. Dad certainly noticed her kick ass, good looks.

Various shots were taken of me on a beautiful, palomino mare at and around the stable grounds. When the photographer left, I went on a trail ride with Dad, Randall and the stable owner. I felt ecstatic, praying my brain would hold together without any side effects from my medications. Happily, none of my drugs were messing up my mind at the time. Since horseback riding was such a powerful therapy for my mental state that may not have been possible anyway.

While we made our way along a dry riverbed trail about a mile away from the stable, I heard a screeching growl. The horses stopped and nervously jerked back a few steps. Then I saw it. A mountain lion crouched on a boulder in front of us at a bend in the trail. Before I could yell at everyone to watch out, and hang on if my horse bolted, six barking dogs ran past our horses and chased after the surprised, frightened lion. I didn't realize the stable owner's dogs had been quietly following behind us all along. So much for my affinity with a big, hungry cat. I wished I had a chunk of meat to throw at it. I didn't like the dogs going after it even though they probably prevented one of us from getting mauled, most likely me.

After that incident and the fact it would be getting dark soon, we headed back to the stable. Soon the dogs would stop chasing the lion and catch back up with us. Randall asked me his last question when we were back in the car. "Sara, if you could go on a trip anywhere you wanted, where would you go?"

"Sometimes, I dream about traveling in a time machine, so I'd like to go on a trip back in time to see how the earth looked before humans messed it up. You know, when it was pristine—when mountain ranges jutted up out of the earth, framed by clear, blue skies. I bet the earth was at one time so incredibly beautiful it would bring tears to your eyes to see it."

It's funny, once we were home, I didn't want to scare Mom by telling her about the mountain lion, but Dad did. Dad didn't want to tell Mom about the foxy stable owner, so I did. The day was a good one.

38. CYBER FRIEND

Computers made a real difference in my life and I became a genuine child of the information age. My long, slender fingers danced across the keyboard with amazing manual dexterity. The Internet became my limitless library to the world giving my brain all the mental exercise it could handle. My neurons happily fired

away, saturating my mind with positive thought waves. E-mailing became my primary method of communication. In this way, I became friends with Anastasia, my cyber friend from St. Petersburg, Russia.

Anastasia and I had much in common. She studied English and her writing was excellent. I, on the other hand, could not understand a second language at all, not even Spanish, which was my own mother's native tongue. Shame on me, I had no excuse for not being bilingual when the opportunity followed me around on a daily basis. Yeah, I know, too much medication, right?

I kept all of our e-mail correspondence filed under "From Russia with Love." In the beginning, our emails were pretty much simple queries about our culture differences, the kind of food we ate, fashion and, of course, how stupid boys were. You would think we were doing research for a school essay on each other's country sans politics. As we became more familiar with one another, it became apparent how much we were alike. If you remove politics, all of us on this earth are like brothers and sisters, part of the same human family. We are all just individual pages in the book of humanity.

We really enjoyed sending pictures with our e-mails. It's such a well-worn cliché to say it, but pictures really do speak a thousand words. Anastasia had a rare, exotic beauty, the result of combining Nordic and Slavic genes. She worked as a tour guide at the Hermitage Museum, one of the great repositories of the most significant artwork in the world. We both loved art in all its forms. The thing that made our friendship click most of all was our open-mindedness.

With all our personal similarities, our lives were a study in contrasts. She lived in a cold climate with frigid winters while I lived in a warm climate with furnace hot summers. She lived in a great city full of history where people filled the streets. I lived in a modern city where cars clogged the streets. Her trips away from home took her to places like Kazakhstan while my travels stayed within the borders of the continental United States.

When Anastasia suggested I write a book about my unconventional life, I didn't take her idea seriously at first. I mean, how could I, without any formal education, write something longer than a one-page e-mail? What would I write about—my getting seasick on a whale-watching boat? Hardly. Finally, after mentioning the idea to Dad and with his gentle prodding, I decided to go for it, but how? I was more comfortable creating images with charcoal pencils, brushes and computer programs than with words. How could I turn personal anecdotes into an interesting memoir?

Sitting at my computer took on a new purpose, a new urgency, for better or worse. Maybe, my story would help bring more awareness for organ donation or just end up rejected, with the paper only good enough to burn in a fireplace. My method would be to simply splash words around in my computer's word processing software as if it were an abstract painting—an objective fragment here, a subjective fragment there—until my memory banks were drained of what I wanted to succinctly say. I would attempt to construct bite-size chapters into a final collage of words that no one chokes on out of boredom. The concise result of my writing style should give literary critics a field day. It is said that less is more, right?

I began typing furiously on my keyboard. “My name is Sara Jones. This is not my actual name. There are few real names of people or places in this fractured memoir of survival, only pseudonyms, although, I assure you that all else you read is based on hard fact. In this fast-changing and litigious world, I doubt I would be able to get away with describing real people and institutions in my usual brutally honest way. I am still far too young to have had any significant corruption of character and, like a hidden blessing, my afflictions have provided me with a quasi-protective barrier against the eclectic drama and comedy that defines humanity.

“I am innocent, but far from naïve. I say what I think, without being euphemistic or politically correct. With all that has happened to me during my short stay on this earth, I could easily have mastered the art of jaded cynicism, but that only feeds depression, which is the constant enemy I refuse to let take me down. Much of my life has been spent in hospitals, affording me a unique insight into the esoteric workings of the medical establishment—good, bad and indifferent.”

Whew! That spate of words burned my brain lobes. I'm sure some smoke came out of my ears. A subject I would have had a great deal of trouble writing about was the ethics involved with organ transplantation. I would literally be opening up Pandora's Box with controversies, including those in my own mind. Not a good thing.

What about the sources of organs and the way they are procured? What is the best way to get organs and decide who gets them? Should someone get another organ if the first or second one fails? What about paying for organs? Do alcoholics deserve a new liver? Should organs only go to those who can afford them, through insurance or other means? What about consent? Perhaps, the biggest ethical dilemma of all, when does the death of the donor actually occur?

Is it when breathing stops, when the heart stops, or when the brain no longer functions?

Since these topics were not related to my story, I never attempted to write about them, thereby preserving my sanity. My hope is that future, medical science will advance enough so that transplantation will no longer be necessary, but for now, organ donation saves lives. That is what altruistically matters. And no one on this earth should be denied a life-saving transplant because of money and/or political issues. Life is a priceless asset.

39. NOT SO BRAVE

On December 7, 2008 I reached my twenty-first birthday without any fanfare. During my teen years, I couldn't wait for that date, thinking how cool it would be to order a draft beer and consume it legally. I thought it would be like some kind of rite of passage into the adult world and I would become instantly mature. Not true. I have a knack for bullshitting myself, sometimes. Funny how I desired to reach an age that ended up meaning nothing special to me once I got there. It did, however, mark the beginning of a new life for me in terms of getting my attitude back on a positive track and feeling better health wise.

Looking back at my twenty-one years, I had a lot to be angry about, but more importantly, I had a lot more to be thankful for. Mom, Dad and Tommy were the most loving and supportive family that could ever be imagined. Wonderful people, especially Jane and Susie, had become part of my life. I had a short-lived, but precious relationship with a valiant boy named Mark. All my doctors and nurses, with few exceptions, were the best in the world. I was blessed to have a special affinity with animals. Most of all, I was grateful beyond all measure for receiving the gift of life.

With my lowered immunosuppressant drug dosage, my emotions stabilized. My mind belonged only to myself again. I was eager to attend college with a major in zoology. My family support system remained strong and intact. I knew there would still be some setbacks from time to time, there will always be some bumps on the road of life. I would always carry the reminders of every needle that poked me, but I didn't care. I just stopped dwelling on it.

Jane called to wish me happy birthday and asked me to meet with her at a cemetery. She told me it was very important that we talked and she wanted to do it there. The next morning, she sent a limo to pick me up and I was taken to a pine-forested peninsula that jutted like a bent elbow into the sea. It was a

tranquil place, a quiet coastal enclave twelve miles north of downtown Delta City, although still within the city limits. The driver managed to get there in less than four hours, circling around the heavy traffic of the downtown area.

The limo slowed down and entered the cemetery through a pair of rusted iron gates, which have remained open for decades. A lichen-encrusted plaque was barely visible on one of the cement block, gate pillars. I had arrived at Luna de la Alma cemetery. It meant Soul of the Moon. I thought the name was romantically perfect for a seaside graveyard from where you could see the moonlight waltz across the sea swells at night.

The limo pulled up next to a stone mausoleum and parked next to a black Bentley. I spotted Susie walking toward me as I stumbled out with stiff legs. We greeted each other with a hug and she led me along a gravel path to where Jane waited, sitting on the grass next to her son's grave. A blanket of fog from the ocean covered the graveyard chilling the air. Fingers of mist mysteriously curved around headstones in surreal patterns. The climate on the peninsula remained damp most of the year making the cemetery green with plant life. There were no beaches here, only high, clay cliffs scarred from erosion and mudslides. The roots of pine trees did their best to hold the cliffs together until, one by one, they fell into the surf below in defeat.

"Sara, thank you for coming," Jane said, hugging me strongly. "I hope you don't mind my wanting to talk to you in a place like this. I wanted to be near my son."

"I don't mind at all. It's really beautiful here. I like it," I replied honestly, holding back my tears. I watched Susie turn and walk back toward the cars. I knew what Jane was about to tell me.

"After my son, Zack, passed away, I was going to spread his ashes over the ocean, like I did for my late husband. Then I realized I wouldn't be able to go to him like I can here. I guess you could say I didn't want to lose the spiritual connection. I can come here for solace, to bring flowers, to talk to him. You understand?"

"Yes, I do. I really do," I said. I felt my heart would break for Jane. I knew she loved her son very much.

Jane continued, moist-eyed. "I first thought that there would be nothing left of Zack but a dream, but there was you, a beautiful girl whose courage in the face of adversity makes you even more beautiful."

"What do you mean? I'm not so brave."

“Sara, do you believe in dual spirituality? I mean, that two souls can share one physical body?”

“I suppose so. Why not? There’s no reason why it couldn’t happen, I guess.”

Jane drew in a deep breath and in a broken voice said, “Sweetheart, You have my son’s heart and liver. Zack is your donor.”

Even though I already knew, it was like an emotional shock wave hearing it from Jane, Zack’s mother, my friend and my angel on this earth. We held onto each other and cried for what seemed like an eternity.

Jane managed to speak again through her tears. “Sara, you proved that Zack didn’t die in vain. He lives on in you. I’m very happy knowing that.”

I stared at Zack’s headstone, wondering if what Jane said could be true. If so, and I began to believe it was so, then why would I be blessed in this way? Somewhere, I once heard that innocence was truth in the eye of God. Was I innocent? Isn’t truth only a point of view? What about having some of the characteristics of the organ donor passed on to the recipient? Did Zack pass anything of himself to me? While gazing lovingly into Jane’s eyes and with unexplained impulse and spontaneity, I said, “I love you, Mom.”

A ray of sunlight broke through the fog and Jane felt her pain lift along with the mist. So did I.

EPILOGUE

I left Luna de la Alma cemetery with Jane to spend the night at her nearby beachfront home. Susie chauffeured us in the Bentley while we sat in the back reminiscing about Disney World and Las Vegas.

Later that evening, I was alone in Zack’s upstairs bedroom, which overlooked the swimming pool where he died. I sat on the edge of his bed, holding a framed picture of him wearing his high school, football uniform. I admired his rugged, good looks and knew he easily attracted girls. Judging by his picture, I would have wanted to be one of them. Strangely, I felt familiar and comfortable being in his room. I have experienced déjà vu before, but this time it seemed extraordinarily real.

I climbed into Zack’s bed at midnight and lay under the blankets for several hours before finally falling asleep. My mind raced, as it usually did, with a conglomeration of thoughts. This over capacitance of mental activity made me feel like my neurons were going to burst out of my skull with the force of a 9MM bullet splattering a watermelon.

I wondered, I pondered and I contemplated one thought after another, often unrelated, like my mind was a virus-infected computer. I wished my brain had the ability to reboot like a computer. It didn't, so my mind skipped around from one subject to another without focus. I thought about how nurses were stuck between a rock and a hard place (doctors and patients) and how awful it was when they had to do a "turn and baste," rolling over and cleaning up a code brown patient. Then my thought pattern shifted. I wondered why one of my boobs was larger than the other. I heard Dad's voice telling me to never ask for help during a nurse's shift change. I visualized my paracentesis puncture site leaking out ascites fluid days after the procedure. Like a slide show, a new vision or thought kept popping up. I was in an MRI machine screaming when the powerful magnets began pulling my pacemaker out of my body.

Was I becoming psychotic or having leftover hallucinations? My brain activity reached for the farthest point of no return, to the edge of awareness, until it fell into the calmer dimension of sleep.

"Sara," a reverberating voice said. "Can you hear me?"

"Yes. Who are you?"

"You *and* I."

"What? Are you God?"

"No."

"Are you an angel, then?"

"You may think of you *and* I that way."

"Why can't I see you?"

"I'm not a vision."

"Then I'm dreaming."

"Yes *and* no. We are only a message. Nothing more."

"Okay," I said, talking in my sleep. My body was twitching. "Are you Zack?"

"I am he *and* I am you."

"Can I be with you *and* Mark if I die?"

"Do you want to?"

"Maybe."

"There are many people who want you to live."

"How do you know that?"

"Prayers. Your family wants you to be with them. Jane and Susie want you to be with them. Everyone who knows you. Your father has a powerful soul that kept him alive many times. So can you."

“Why? For what purpose should I live? Death is so peaceful and I’m really tired you know—burned out.”

“For everyone who loves you *and* those who will come to love you.”

“What about God? Does he want me to live?”

“It’s up to you.”

“Why has God made me suffer if only to spare me?”

“To show others through your example that giving life through organ donation has His blessing. Donating life is the greatest and noblest gift of spiritual love that can be made.”

—end—

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