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Face of a woman, body of a child

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Face of a Woman, Body of a Child

By
Jill Dopf

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of

MASTER OF ARTS

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Program of Study Committee:
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This is to certify that the master’s thesis of

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has met the thesis requirements of Iowa State University

Signatures have been redacted for privacy
Table of Contents

Introduction.....................................................................................1

Learning to Walk....................................................................................5

Captured..............................................................................................16

Face of a Woman, Body of a Child......................................................24

Un-Walking............................................................................................44
Introduction

As a young child, I was simultaneously intrigued and repulsed by the sight of a Barbie doll. I wondered at her flawless flesh and the perfect symmetry of her body and face. Yet on closer examination, I became frustrated by her rigid frame. Barbie’s slender ankles, frozen in the contours of a high heeled shoe could not support her body weight. She possessed a mature face and a fragile body that required continuous attention. Drawing the sleeve of a shirt, a miniature tube of fabric, over an arm frozen in flexion was an exercise in patience. Her neck was no more yielding. As I attempted to prod her face forward, I found her head mysteriously locked in place.

Sometimes a friend would inquire about the whereabouts of my Barbie collection. She’d kneel before my toy closet and open her own Barbie traveling case—a pristine white ensemble adorned with rose metals and a shiny gold latch. She’d gasp in horror as I reached inside my Tupperware bucket and withdrew a semi-nude doll from a mass of tangled limbs—stilettos heel wedged in a mass of tangled hair, three purse straps looped about her ankle.

In time my Barbie dolls were relegated to the lowest shelf on the toy closet. My attention turned toward my growing collection of baby dolls. I preferred the feel of soft plastic against my skin, a torso filled with beans that wrapped over my knee or the crook of my arm.

I thought little of Barbie until the seventh grade. As I stood among my friends and practiced a cheerleading routine, I felt the probing eyes of my coach upon me.

“Straighten your arms,” she’d insisted.
I gazed at my arms and realized they were locked in a semi-flexed position. For the remainder of the practice I bunched my sleeves of my sweater about my elbows to mask the deformity.

Alone I pondered the mystery of my body. My Achilles heel had assumed a permanent “tip toe” position by the age of six. Despite two surgeries to lengthen the tendon, they’d once again resumed the mysterious posture. Bending my neck forward, I found it to be mysteriously locked in place like bone meeting bone. As I studied the unusual changes taking place within my body, I realized I’d come to resemble the doll I’d always despised.

I found few answers at my neurology appointments. Though I’d carried a diagnosis of muscular dystrophy since the age of four, my doctors were at a loss to assign a particular name to my rare condition. Especially in my teen years, I’d despised these visits. I felt like a specimen—a rare phenomenon closely scrutinized, but never completely identified.

I’d grown frustrated with the lack of information provided by my physicians, and decided to pursue the study of genetics in college. At the age of nineteen, I finally found the answers I’d been searching for. As I sifted through a stack of medical journals, my eyes locked upon the photo of a young Turkish man. His arms were frozen in flexion and his neck was hyper-extended. As I studied the photo, I realized we shared the same condition. Within the year, my own diagnosis of Emery-Dreifuss muscular dystrophy (EDMD) would be confirmed by my doctors.
I entered the graduate creative writing program eager to bring closure to my life. I'd wanted to purge all of the traumatic experiences of my life and hide them within a neatly bound volume I could tuck away on a book shelf. By the middle of my graduate program, I found that I was swimming deeper and deeper into the murky waters of my own genetic illness. Despite the exciting developments offered by my researchers at Johns Hopkins Medical School, I found myself even more perplexed by a body that seemed incapable of change. As I surveyed my writing, I realized I had very little to say about my progressing muscle weakness. Instead, I found that my writing revolved around questions of body image.

In the middle of my graduate career, I received a phone call that would forever change my life. For the first time in my life, I had the opportunity to speak with a woman by the name of Mary Blue who shared my diagnosis of EDMD. To our amazement, we shared our experiences and realized we had lived very similar lives in neighboring states.

In the midst of my joy, I was overwhelmed to learn that Mary was experiencing heart failure for the second time in her life. As our friendship blossomed, concern for Mary’s health remained ever-present in my mind. Though heart failure, especially at a young age is a rather uncharacteristic in cases of EDMD, Mary had received a heart transplant in 1988 at the age of 24. By the summer of 2001, this second heart was also beginning to fail.

Despite her own advancing cardiac and muscle weakness, Mary shared with me the greatest gift one person could offer to another. It was Mary’s wish that I learn
to accept my own advancing muscle weakness with the same grace and dignity she
had displayed in her own life. As I struggled with my own fears for the future, I found
peace and great comfort as I visited Mary at her home in the spring of 2002.

Mary Blue passed away August 9th, 2002. In my essay, "Un-walking," I
describe my final conversations with Mary and strive to share the dramatic impact she
has made on my life. Despite more than twenty years of medical consultations, I feel I
have experienced the greatest spiritual growth through my friendship with Mary. I no
longer seek a "cure" in my life, but instead, I accept myself just as I am.
Learning to Walk

“Bob’s grandmother walks like a sleepwalker.”

My aunt Janice gently nudges my mother’s arm. The clink of overturned china tea cups echoes into the adjoining living room. An elderly woman teeters about the dining room table, clearing up leftover napkins and crumbs of cake. Her gait is stiff and robotic. She pauses periodically, reclining her rigid, lanky frame against the buffet. Her fingers grasp the backs of chairs for balance.

“I’m telling something isn’t right,” she insists.

My mother tries to focus her attention on the woman in the center of the living room sharing the answers to a round of Bridal Shower Boggle. She reassures herself that the woman’s odd movements are merely a sign of old age and stares intently at her game card.

“Watch her,” my aunt cautions as she tugs her shirt sleeve.

Reluctantly my mother glances in the direction of the dining room. A lump swells in her throat as she studies the slow, sluggish steps, feet that barely clear the carpet. The woman walks with the posture of a sleepwalker—arms levitated at her sides, a face that stares straight ahead rather than scanning the floor. Her feet appear heavy as if sealed to the floor by a pool of molasses. Stepping through the kitchen doorway, her fingers grasp the doorframe to maintain her balance.

My mother shakes her head as if awakened from a bad dream. Surely her observations are a figment of her imagination, pre-wedding jitters in full swing. She stares intently at Dorothy, her future mother-in-law. She moves without hesitation about the room, stepping in and around the conversing women. She lunges to the floor
to retrieve discarded wrapping paper, and rises without effort. Though she appears of medium build, her slacks seem to be cut just a bit too full in the seat. The extra fabric bunches about her ankles and the cuff is frayed as it is caught beneath the heel of her shoe. The only oddity is her preference for high-heeled shoes. My mother recalls a recent shopping trip and Dorothy’s hand ushering away the boxes of tennis shoes and flat heeled sandals.

“I only wear shoes with a heel,” she’d insisted.

There’s nothing wrong, my mother repeats over and over to herself. She recalls sitting on the sofa between Bob’s mother and grandmother pouring over photo albums. The two women appeared vibrant and healthy as they posed side by side clutching golf clubs, and in another photo, shaking hands over a tennis net.

My mother opens her shower gifts, her fingers trembling as she wrestles with bows and scotch tape. She catches a glimpse of her vacant eyes as a butter knife passes through her hands. Numbly she passes along a set of measuring cups and a toaster. A thick white album gathers the most attention from the circle of women. It’s a couple’s scrapbook, a portfolio of photo displays and blank memo pages. The sections progress chronologically—*Our Engagement, Our Wedding, Our Honeymoon*. On the final page, *The New Baby* is spelled out in wooden block lettering. A vacant cardboard oval stares back at her. She imagines a face in this empty space, and then she glances toward the grandmother’s waddle. The nervous rumblings return and she stares intently at the frame willing this nameless face to answer back.

*   *   *
My father never challenged his demerits. Standing stone faced alongside his fellow R.O.T.C. students he’d tuck the pink slips of paper into the pocket of his slacks. Though the booming voice of the sergeant hovered inches from his face, he didn’t flinch, and he didn’t argue. With the strike of a wand against his heels, he aligned his feet in perfect side to side military fashion. His calves ached in this unfamiliar posture and his muscles twitched and threatened to give out, but still he stood. He’d wait until the sergeant moved by for the moment he could relax once again and slide one foot slightly ahead of the other.

In a field where a fallen arch or anything less than twenty-twenty vision would garner dismissal, my father carefully guarded his secret. Though he was considered a healthy man, even by military standards, his Achilles tendons were too short, resulting in a heel that hovered nearly an inch above the floor. He’d masked the oddity with shifts in posture and a carefully selected heel size.

His fellow students rarely questioned the demerits lining the base of his locker. A strong cadet with perfect attendance, he was only reprimanded for lapses in posture. Though he walked with a slight waddle, memories of this disappeared as one watched his arms and legs move deftly about the controls of an airplane. In the rare moment his gait or marginal fitness test scores were called into question, he’d mention a childhood brush with polio, then abruptly change the subject. An army physician had lingered before him as he stood in formation his freshmen year. He rubbed his fingers against his chin, as he eyed my father’s slender calves and slight breech of posture. He’d requested my father see him, but this was an appointment my father never made.
During the fall of his sophomore year, my dad stood in the hall with the other students, clad only in boxer shorts, cotton t-shirt and navy knee socks. Peering around the corner, he saw the same physician headed toward the gymnasium. Without a word to his friends, he ducked down a side hallway, but as he turned a corner, he ran into the army physician. The army doctor stroked his chin and looked my father up and down. A gust of wind from the open doorway ruffled the sleeve of my father’s t-shirt. The physician turned his arm over and over, pondering the full muscles of his forearms and slender biceps of nearly half the circumference. Later that afternoon, a slice of muscle was cut from his biceps. In the bright light of a microscope, the language of his uneven steps was spelled out in misshapen muscle fibers.

* * *

As a toddler, I was mesmerized by my father’s footsteps. I’d lie on the floor watching his shoes upon the ceramic tile, heels never striking the floor. As my mother stepped onto the porch to offer his lunch and a kiss goodbye, I’d slip my feet into his shoes and ballerina step across the floor.

My father’s shoes were the perfect size for car races. Crawling about on all fours, I’d slip my palms into the soles of his shoes. At first I positioned the tips facing forward, but the snag of the carpet slowed my stride. Turning them backward, unblemished heel in the forward position, I discovered they moved effortlessly over the carpet.

I’d wanted to share these same mysterious footsteps. I’d slink about the bedroom, propped on tip toes, imagining a troll hiding in my shoes, pinching the flesh
of my heels. I'd close my eyes and imitate the step-pivot, step-pivot of his tall and
lanky frame.

My mother listened closely to his footsteps as well. As she folded laundry in
the basement, we’d hear a thunderous boom from upstairs echo across the floorboards
and rattle the ceiling fixtures. She’d dart up the stairs and lean her ear against the wall
of the adjoining room. She’d pause for a few moments, listening for the sound of my
father crawling across the floor and drawing himself to his feet, before returning
unnoticed to her work. It was an unspoken understanding. She never rushed to his
side, even as he fell in public places.

Only in moments of true penitence did my father share the language of his
mysterious steps. We’d kneel before the communion rail at church, the upturned soles
of his shoes flanking the bright red carpet of the altar. As I awaited the blessing, I’d
crane my neck, eyeing the tuft of navy dress sock peering out the hole of each of his
shoes. For previous pairs, my mother had attempted to patch the holes, but inevitably
the ebbing of leather would occur in the same place.

I carried my fascination with shoes to my pre-school. As we walked the
hallways, I’d eye the shoes ahead of me trying to match the pace step for step. After a
few yards, I’d lose my place in line. Before the pain, I’d hear the slam of my head
hitting the tiled floor and the smell of dust filling my nose and mouth. Raising my
head, I’d see the shoes of my classmates in a semi-circle around me, and then I’d hear
the harsh click of high heeled shoes.

“You walk just like your father,” said my teacher as I fell one day.
I’d wanted to blurt out the good news to my mother right away, but she urged me to wait a moment as she unloaded the groceries and tucked my brother in his infant seat. I swung my feet from the kitchen chair, gently striking the rung. Turning the shoes over in my lap, I eyed the tread, searching for the same tell-tale weathering as my father’s shoes.

Moments later the phone rang. My mother cradled the receiver against her shoulder as she continued to prepare lunch.

“It’s your teacher,” she mouthed to me.

She listened without speaking for several minutes. Her head dipped slightly between her shoulders like a bird seeking warmth. She rocked gently from side to side, rubbing her temples with her fingers.

“I have a pot boiling over,” her voice trembled.

The stove top was empty. We were having peanut butter sandwiches.

“Please, I can’t talk right now,” she said as she turned her face toward the wall, tears spilling over her cheeks.

Unnoticed, I slipped into the living room. After a faint goodbye, my mother slumped to the floor, hands over her face. She began to sob, her cries drowning out the beep of the telephone receiver in her lap. My two year old sister, Janet pushed a chair about the room, and my baby brother kicked and cooed in his infant seat. I’d wanted to sit beside her, but I watched and waited, peering around the corner of the adjoining room.

* * *
Later, I attend the birthday party of a pre-school classmate. At the close of the party, we begin a walk toward a park at the foot of the street. I’m anxious to walk with my friend Elizabeth and I position myself at the front of the line. At first I keep up, but then I start to fall behind. My legs sting and I have to resist the urge to lie in the grass. I’ve never felt this way before.

Soon the group disappears around a bend in the sidewalk, only their balloons visible above the shrubbery. I walk faster and faster, but my shoe snags a cleft in the sidewalk and I fall. Blood oozes through my tights and stains my new pink dress. I hear the footsteps of mothers behind me and soon I am pulled to my feet, a new balloon tied about my wrist.

As we arrive at the park, I sit apart from the children. They’re playing a game of Duck-Duck-Goose. I watch their strong legs run about the circle of shrieking children. I eye the road searching for my mother’s station wagon.

“What’s wrong with me?” I ask my mother as she arrives to pick me up.

“Nothing’s wrong with you,” my mother says as she holds my face between her hands. “You’re a perfectly wonderful little girl.”

“No!” I say as I point to my ripped white tights stained with blood and grass stains.

“My legs don’t work right.”

Two boys run past the car, spraying one another with squirt guns. A young mother and her daughter sit beneath a willow tree sifting through the contents of a party basket.
“You were born with weak muscles,” she explains as she tucks a loose strand of hair behind my ear.

“Why?”

She sifts uncomfortably in her seat.

“Well, children look like their parents and because dad was born with weak muscles, you were born with weak muscles too.”

I remember my dad’s heavy steps in the snow as she struggled to carry my sled up the hill last winter. On the final snowy day of the season, he suggested a trip to the local pizza place as I stood before him, decked out in my snow gear. I’d played alone outside in the snow as we returned home, but I didn’t have much fun. I fell nearly every step and spent most of the time making snow angels. As I lay on the frozen ground, I’d remembered the gleeful faces of children perched on their father’s shoulders as they effortlessly ascended the snowy banks of the golf course.

Later, as I sat on the edge of the tub basin, my mother tugged my damp socks from my feet. I asked her why dad didn’t want to go to the big hill anymore.

“You know he wants to take you, but his legs aren’t very strong,” my mother replied.

I sat silently for a moment, a pout on my lips, my arms folded across my chest.

“It’s really important that you don’t keep asking him to take you there. It makes him feel sad. Do you understand?”

Now, I’m instantly transported back to this moment as I sit beside my mother in the car. I remember the awkward lump in the back of my throat. It made me angry
that there was something different about my dad. Now I realize I am part of this secret and I slump lower in my seat, prodding my finger about a hole in my tights.

"Why don’t we just go to the doctor?" I insist as I sit upright in my seat.

"The doctors don’t know how to fix this," she says.

I reach over her grabbing the steering wheel with both hands. It’s locked in place, but I rock it furiously.

"Drive me to the doctor," I shout through clenched teeth.

"Honey, I would drive you anywhere in the world if there was someone who could help."

"I want a shot!"

She slides her palms beneath my arms and tucks me back beneath the safety belt. I growl and kick the dashboard with my feet. My mother doesn’t stop me. Soon I fall back against the seat exhausted.

"Will my legs be this way forever?" I ask.

My mom exhales and rests her neck against the headrest.

"Your legs will be strong in heaven," she says.

She starts the car and we move slowly through the city streets. A party hat crunches beneath our tires and I turn in my seat, eyeing the crumpled hat as it bounces along the curb.

* * *

My dad cradles my feet in the palms of his hands, massaging each Achilles tendon, willing it to grow and strengthen. We perform this ritual every night
following my bath at a time my muscles should be most warm and supple. He asks me to nod when I feel the strain of stretched muscle, but I feel nothing. Out of the corner of my eye, I see my sister reclined before the television. It's never her turn for stretching exercises.

My dad glances at the black and white photos scattered about the floor. Children in black leotards demonstrate proper physical therapy techniques. In some of the photos, the therapist is cropped out of the frame, yielding a set of pasty white hand and no face. I find the pictures disturbing, so I often turn my head away. The nameless children never smile. They never cry and they never show anger. They simply stare toward the camera with subdued, glazed over expressions.

I hate the fact these photos belong to me. They're stored in a manila folder, my name spelled out in thick black letters across the cover. An overly perky physical therapist placed the photos in my parents' hands, urging us to think of this as play time. Family time. A time for talking. But as I lie on the living room floor, my wet hair seeping into the carpet, I grow sullen and withdrawn. I don't want to talk and I don't want to be different.

One day I decide to hide the folder. As evening approaches, I see my dad shuffling through the bookshelf and a stack of papers. We begin the exercises and he makes no mention of the missing folder. To break the tension, he starts a tickling match. I sit on his legs and remove his socks and shoes. We share a thin layer of callouses on the soles of our feet. Our heels appear nearly identical—reddened and chaffed from the friction with the heel of a shoe. Pinching his Achilles tendons, I realize they are just like mine—a narrow tube of rigid tendon, slinking back toward his
calves. He watches me with steady, unblinking eyes before drawing his legs beneath him and drawing his pant leg over his heels. In this moment, I realize he hates these exercises as much as I do.

Alone in my room, I slide the folder from beneath my mattress. Spreading the photos about my bedspread, I name the children and design a pretend life for each one. I assign them favorite colors and favorite foods and superhuman powers. Then, I rip each photo in half, separating the face from the body. I hide the faces under my pillow, and in the moonlit windowsill, I lay each body. A summer breeze flickers the edge of each photo, seemingly breathing life into each photo.

In the morning I find the windowsill empty. I imagine each child far away from needles and hospitals, but in the days that follow, they return to me, one by one. I find the twisted bodies in the crook of my stuffed animals’ arms, and wedged into the toe of my shoe. Separated from the face, they have no meaning to me. I consider releasing them into a gust of wind or a bubbling brook, but instead I replace each head upon its body. When I see them as whole, it is then I will realize they are free.
Captured

I feel completely humiliated, naked except for the lumpy terry cloth garment encircling my waist. It looks like a diaper. A square of white fabric devoid of leg holes or an elastic waistband, I’m uncertain of its placement on my body. It hovers like a shallow hammock between my legs, barely grazing my skin, funnelling the breeze from a floor fan.

The woman behind me strokes my hair and casts my jewelry on the table beside us. She twists my air into a bun high atop my head. Circling my frame, she eyes her work with the care of a mother preparing her child for the first day of school. I feel my hair slip from the nylon band, cocking the bun on its side. She begins, smoothing each wispy strand of hair in place, and securing it with a bobby pin.

I close my eyes and pretend she is preparing me for a dance at my high school, her fingers wedging bits of baby’s breath in my upswept hair. I imagine myself standing among friends—a hand about my waist, the gentle kiss of a corsage upon my wrist. Parents duck among one another, positioning cameras and prompting smiles. Yet, as the image grows clearer, I sense my true identity. I feel the strap of my sequin purse slide from my slumped shoulder. My head and torso slump to the side like a marionette entangled in its web. Beneath my gown, my concave shape spills over the side of my bra like warm dough pooled against the rim of a muffin tin.

Opening my eyes, I see a camera resting on a tripod. The woman steps behind the camera. Waving her arms in slow methodic circles, she motions for me to move to the left and then to the right. A sheer umbrella dangles from the ceiling, funnelling the hot glow of spotlights.
My eyes dart about the room. Though I’m reminded to stand still, arms to my side, I press my forearms against my breasts and rock gently in place.

“Don’t worry. It’s only you and me and I promise to keep the door closed,” replies the woman as she crosses the room and checks the lock.

She reminds me the photos are part of my scoliosis file. I’ll return in several weeks for “after photos.” I don’t remember signing a release form. My parents signed dozens of informed consent forms. They were advised of the complications of surgery, the protocol of the operation, and post surgical follow-up care. Perhaps this release was buried somewhere in this cumbersome paperwork.

Stuffed animals peer from a plastic crate. A man’s silk tie spills from a lost and found box. An empty infant carrier with cartoon padding lies vacant in the corner. I wonder about the others who have stood in my place. I imagine a woman smoothing her fingers over masectomy scars, scars she is too afraid to show her husband. I imagine a young mother blinking back tears as she kneels on the floor before her infant daughter, urging her to smile through a cleft palate. I wonder if these people cried. I wonder if they looked away from the camera, but most of all I wonder about this photographer and how she survives in a room where there is no healing, only documentation.

She moves fluidly about my frame, adjusting the garment about my waist. I wonder how she arrived at such a position. Is there an application? An interview? Did she begin her career at Wal-Mart taking photos of children? I wonder if she, alone in this studio, passes before the lens of the camera, or if she slinks along the periphery, side-stepping the camera’s aim.
“Pretty hair. It’s a shame to put it up.” replies the photographer as she readjusts my hair once again.

My hair was once my protection. Though baby fine I’d imagined silky flowing locks washing over a body that had betrayed me. I dreamed for hair so long and full that I could drape it around my body like a giant silk scarf. I longed to cloak and camouflage my deformity, reorienting the eye like an ornate petal draped over a wilted pistil.

I first learned of my scoliosis while working an after school job. Dressed in my fast food uniform, there was no room to hide. The wayward lines of my shirt accentuated my curvature. My orange neck tie cocked curiously out of place. I remember the gasp of an elderly couple as I turned to fill an ice cream cone and later their concerned faces peering out from a nearby booth, untouched ice cream melting on the table. I sensed they were concerned that something was wrong with my back. Alone in the employee restroom I locked the door and removed my shirt. Under the glare of a fluorescent light, I studied my reflection in a hand held cosmetic mirror. I grimaced at the jut of my shoulder and a misplaced mound of tissue, like the dome of a watermelon rising from my back. I blinked back my tears and returned to work, glancing periodically at my reflection in the chrome of the coffee pot machine.

The next few months remain a fog of angry outbursts and slamming doors. Then I remember the hum of the x-ray machine closing about my body, my flesh pressed against cool metal. I remember turning on every faucet in the waiting room restroom, my body sprawled on the floor, forehead braced against a granite sink, and a terrifying primal wail. Then, I remember the grainy bleat of my mis-pronounced name
from the bathroom wall speaker, my vacant eyes following the swish of polyester slacks. I remember bending forward to touch my toes in a room full of strangers, peering between my legs to see eight pairs of khaki slacks and leather shoes. Then I see my x-ray—my spine like a serpent in water, smooth curves immersed in a shallow dark pool.

I lost my voice that day. A part of me will always remain in that Mayo Clinic bathroom, reverberating from stall to stall, but never free of confinement. I listened without reaction, without emotion as the doctor described my case as extremely progressive and life-threatening. He pointed to the fist-shaped bulge, my heart, in the center of my chest and my spine advancing toward it. He explains that as scoliosis progresses my curving spine will eventually rest upon my heart and lungs, impeding their function.

"Suppose we leave. What if she doesn’t have the surgery?" questioned my mother as she leaned forward in her chair.

"Jill will die," replied my doctor.

My doctor described the surgical procedure. Two steel rods would be affixed laterally to my spine, forcing the curved spine back into a near neutral position. The rods would never be removed, he explained.

My mother sifted through her purse retrieving a pocket calendar and selecting surgical dates with an intern. The doctor and a circle of medical students swarmed about my x-ray. Alone on the exam table I felt the crush of my chest and my slow stifled breath. Death no longer remained an obscure concept. It had a movement. A force. A feeling that was tangible and real. They could resurrect me, but I wondered
about the girl who would return in my place. Would she live as a ghost, invading a 
life destined to end at the age of fifteen? I stared down the ominous silhouette of my 
x-ray and prayed for one last coil, one final snuff of breath.

Now the gentle strains of Muzac waft from a ceiling speaker. The sparseness 
of the room disturbs me. There is no place to ground myself. No metal stool. No 
plywood draped in fabric. The sweaty soles of my feet mesh with the paper cut outs 
affixed to the floor six feet before the camera. I'm allowed no movement. My role is 
defined. I bring nothing of myself to this shoot.

My greatest fear is that those who gaze upon me will perceive that I am dulled. I imagine a young intern sifting through page after page of medical photos, sipping a 
cup of coffee. There is no connection to this obedient figure that stands motionless in 
the face of humiliation. The pictures blur one into the other. Maybe he'll contemplate 
my existence on the drive home from work. Perhaps he even wonders about my life 
outside the boundaries of this photo. Then stepping into the foyer of his home, he 
drops to his knees and wraps his arms about his toddler age daughter. He savors the 
tickle of her matted curls burrowing into his face. Later that evening she throws her 
plastic dish onto the ground, spraying the kitchen cupboards with green beans and 
applesauce. He turns his face from her shielding his grin. He knows more than the 
parents at the park who complain of their children's outbursts. He knows more. Has 
seen more. Life dwells in this battle of wills. In this moment he loves her defiance. 
Her anger. He will think once again of this image, the rigid frame and the masked 
eyes and he will hug his daughter and reassure himself she is nothing like the girl in 
the photo.
A matter of months may have changed my impression of this experience. I am fifteen—lips that have never been kissed, a body that has never been touched. In a matter of moments, my brain is swarmed soaking up this encounter like a sponge.

“Do you have any pets? A favorite color?” the photographer asks.

I offer only monosyllabic replies.

I wonder if I will ever feel the touch of another without the click of a shutter echoing in the background. As I return to school I will excitedly answer my friends’ questions. I’ll talk about the anesthesia, the hospital, the pain medication, but I will never speak of this room. I will study my friends from a distance, fearful of the new found confidence they display in their bodies. I will return changed and shameful.

I study my reflection in the spotlight’s long cylindrical pole. Shifting from side to side, I capture a single feature at a time—the rosy crest of my breast, a single eye blinking back at me. The remainder of my body blurs at the periphery, dissolving into infinite rays of light. Craning my neck toward the dome of the spotlight, I see the reflection of my entire self—a face that attracts, a body that repels, and a soul that dwells in between.

I do not want to know this girl before me. This girl who shivers in the cold, forearms clasped against her chest, finger wedged between her teeth. I want to leave her here in this room of stillness and shame. For to reside within this shard of myself is to accept that different is analogous to deviant.

My mind wanders to my ninth grade classroom. A nurse I have never seen before beckons a row of girls to follow her. She leads them through winding corridors
of the school, rooms they have never seen before. They offer bewildered glances as she leads them into a dimly lit room cloaked in green shag carpet and wood paneled walls. Large round bulbs illuminate a table top mirror. It resembles the dressing room of a movie set. She draws a stack of white garments from a bureau and advises each girl to fully undress and wrap a garment about her waist. Then she leaves the room. Safety is found in numbers. They exchange worried glances. One girl taps an oak paneled door at the far corner of the room. It opens to reveal a woman standing at the center of a photography studio. She motions for them to come inside. The girl ducks behind the door, embarrassed that she is topless. I wonder how long it would take for the school’s phone to ring off the hook, for an army of angry parents to descend, and a television news truck to skid across the front lawn. It is now that I realize my mistake.

I know this will haunt me. As much as I desire the healing of my body, I long for a deadening of my mind and emotions. I will never speak of this to anyone, but for years to come, I will play this scene over and over in my mind, questioning why I did not fight. Why I did not run away. Why I allowed myself to be captured.

“May I adjust this just a bit?” questions the photographer.

I simply shrug my shoulders as she lowers the garment to the widest part of my hips, exposing the prominent ridge of my lower spine, flush beneath a thin layer of skin like a string of marbles beneath silk. I’m prompted to lean forward and touch my toes. A frayed bikini tie slides across my hip. I do not move to replace it. Peering between my knees, I see the inverted image of the photographer. Two tennis shoes perch atop a stool. Skinny arms circle about loading a canister of film. Pressing my thumbnail against my shin, I carve a crescent shaped depression. The photographer’s
directions and the click of the camera blur into a soft buzz like a conversation heard from below water.

I wonder what will become of this photo. I imagine an image of myself with darkened eyes and a nervous smirk upon my face, hovering at the foot of a boardroom table. I’ve seen these photos before. A stark frozen moment of a patient’s greatest vulnerability. The body positioned in a way nature and the photographer dictate, all except for the eyes. Maybe that is why black bars are printed over the eyes of the patient. Perhaps this is done to protect the patient’s anonymity, but I wonder if this isn’t really done to shield the peering eyes of the medical community from the humanity before them.

I hold my forearms against my breasts.

“Honey, I need you to lower your arms.”

For the first time, I do not do as I am told.

The photographer steps from behind the camera and takes a hold of my tear-stained hands. For a moment I imagine our intertwined images, miniaturized and inverted, hovering within the camera.

“I hate you,” I hiss.

She loops her fingers about my wrists, lowers my arms to my side, and disappears into darkness.
Before the numerous falls, before the cries to be carried, my mother was worried. I was born at the fiftieth percentile for both height and weight, but my frame altered subtly during my first year of life. As my mother changed my diaper, she’d eye the slender contours of my buttocks. She worried about this lack of body definition, but I was her first child and she had no frame of reference. As she gathered with friends, she’d lean in ever so slightly eyeing the shape of a normal toddler frame, then stare back toward me, eyeing my willowy build.

She expressed her concerns to the pediatrician, but he’d smile and simply shake his head.

“You’re a new mother, Mary. Jill is a completely normal, healthy child. Despite his reassurances, her protests continued. She’d undress me diaper and all.

“She’s simply a petite child,” he said as he examined my body.

For awhile the doctor’s words reassured my parents. They had described me as delicate and feminine from infancy and as I grew in years, my slender frame seemed a fitting match for my personality. I preferred dresses to all other clothes in my closet, even insisting on a dress as I played outside in the sandbox.

By the age of four, my clothes seemed to hover about my body. I wore clothing several sizes smaller than my pre-school classmates. My thick white tights bunched about my legs, pooled over the tops of my shoes. Sometimes someone’s mother or a teacher would kneel beside me and pinch my legs.

“Your little legs are so adorable!” they’d exclaim.
I’d bat their hand away and duck behind my mother’s legs.

“I hate that,” I’d insist.

At the age of nine, I went for a swim at a local pool with my family. Janet, my seven year old sister and I enjoyed our first trip to the diving boards. As I practiced for my dive, I heard the snickering of two boys behind me. I surfaced from my dive to see my sister scurrying to gather our towels and suntan lotion. She motioned for me to get out, but I lingered in the water, my body wrapped about the rungs of the ladder.

“Why are they laughing at me?” I asked.

“It’s nothing. Really,” she insisted.

“No, tell me.”

Reluctantly she bent down beside me.

“They said you look like a white Ethiopian.”

I climbed out of the water and wrapped a thick beach towel around my shivering body. I didn’t wear a swimming suit for the rest of the summer.

During elementary school, my awkward run and waddling gait were never ridiculed. As a new student joined our class, they’d eye my slight frame, then run toward my tiny arms during a game of Red Rover, but it didn’t take a teacher or a recess monitor to reprimand the new student. One of the boys in my class would grasp his arm and whisper something in his ear. Though I stood out of earshot, I understood the message as I watched the new student search out another weak spot in the chain of arms.
Though I was never teased for my muscle weakness, my tiny build was the object of intense curiosity. In the lunch room students would stare at my little arms and legs. I’d try to bat curious fingers away, but sometimes, if I wasn’t quick enough, I’d feel someone’s hand wrap about my biceps or curl about my ankle.

“Look! She’s this little!” they exclaim as they looped their thumb and middle finger together, simulating the circumference of my limbs.

My friend Melissa would smuggle her mother’s Sears catalog to our elementary school slumber parties. We’d lean in closely, giggling at the photos of beautiful woman in scanty lingerie. Shuffling through the pages we’d select our favorite photo, the body we imagined for ourselves someday. Though my friends often picked the most slender frames, I picked out the shapeliest figure. As my friends ran up the stairs I’d lag behind and tear my photo from the magazine and hide it inside my pillowcase.

In the fourth grade the girls of my class were ushered into the library. Our mothers smiled and waved to us from the corner of the room. The school nurse talked to us about “the change” we would soon experience. We were allowed time for questions, and as we left, we were each offered a paper sack filled with samples of feminine hygiene supplies and pamphlets. My mother treated me to lunch and later, she stopped at a drug store. As I sat waiting in the car, I ripped open the sack and studied the pamphlets inside. I hugged my bony legs against my chest as I studied the drawings depicting the development of a woman’s body. The answers were all here, I
reassured myself. "The change," would happen soon and I'd morph into my new silhouette like a butterfly breaking free of a cocoon.

Back to school shopping proved to be particularly traumatic. I'd eye my sister in the three way mirror of the dressing room. Though she was eight and I was ten, her figure had already begun to develop. But, when it was my turn to turn to stand before the mirror, I'd study my stick straight contours, my jeans as attractive as cardboard cylinders wrapped about each leg.

My mother would rock my brother in her arms, reminding me we had to get going.

"I want the jeans with the hips in them," I told her as we sifted through rack after rack.

I'd search the store, believing the answer to my problems could be found in the perfect pair of jeans. There had to be something in the weight of the fabric or the hue of the denim stitching that transformed one's body. Finally I'd accept a pair of jeans with an appliqué on the back pocket to camouflage my slender build.

In junior high my slight frame stood out dramatically. Though I grew in height, my weight remained unchanged. At the age of twelve I began to menstruate, and I developed small breasts, but I was alarmed by my emaciated body. As I peered out the corners of my eyes as I changed for gym class, and I'd see the developing bodies of my classmates. I pondered the curious jiggle of body fat about their hips and thighs. I'd wanted this for myself, but instead I'd pinch the flesh of my body, a mere covering of skin seemingly shrink wrapped about my body.
In the junior high lunch line, I’d hear laughter and then a body bumping into me from behind.

“Tell her you want her,” I’d hear a group of boys shout.

I’d stay frozen in place listening to the protests of the boy behind me in line. I knew he was the heaviest student in the class. Though I wanted to turn and push him away, I knew he was just as much a reluctant victim as I was.

“Ask her out, fatso!” they’d prod.

As the laughter grew to a feverish pitch I heard a gentle voice in my ear.

“I’m sorry,” he whispered.

“He’ll squish her,” they squealed, before leaving me in silence.

Even the blood vessels of my body seemed perplexed by my wilted frame. Thick blue tributaries rose to the surface of my limbs as if in search of absent flesh. This only added to the curious stares and comments I was subjected to. On one occasion, I remember a girl staring intently at my legs. As the teacher fumbled with the overhead projector, she slipped from her seat and pointed to my legs.

“How does it feel to be old when you’re twelve?” she hissed in my ear.

I showed my legs for the last time in the spring of the seventh grade. I’d chosen to wear a new denim skirt, and as I walked toward the bus stop I heard the taunts of two boys behind me.

“Oh my God! Look at her legs!” they said.
I could clearly hear their words though they lagged fifteen feet behind me. As I sat in the bus seat, I eyed the legs of the girl beside me. My legs appeared as two deflated balloons, sitting alongside her well proportioned, tanned legs. I returned home that day and slid my shorts and short skirts to the back of my closet.

My unusual appearance concerned my mother as well. As we drove in the car I would notice her side ways glances as she studied my small frame. Often she’d pull through the drive thru at Mc Donald’s and suggest an extra meal including a shake. Within bites, I’d become full, but she’d urge to at least finish the milkshake.

My yearly visits to the Mayo Clinic yielded few clues. The focus of the visits was my increasing muscle weakness. I’d move my arms and legs through a series of push and pull strength tests. I could barely contain my frustration by the end of the appointment. There were no answers, no explanations at these visits, only documentation. Not once in my entire life was I ever offered medication of any kind to treat my condition.

“Why do I look this way?” I would lament to my doctors.

“You’re just small,” was the only answer I ever received.

In addition to my underdeveloped body, my neck and spine had become stiffened. It had happened so subtly I’d barely noticed the change, but my piano playing offered the first signs that something was amiss. The beaming smile of my piano teacher turned to a frown during one lesson at the age of ten. As I played she softly tapped my back with a wand.
“You’re so tense,” she said.

I tried to relax, but I felt rigid as if concrete had been poured and hardened within my spinal column.

My teacher sighed and took a seat beside me on the piano bench.

“You have such a gift,” she replied as she stroked my fingers. “You play with so much feeling. It starts in your heart and travels to your fingers, but what happens here?”

Her fingers traced my stiffened back.

I remained silent and shrugged my shoulders.

At the age of ten I’d memorized all three sections of Fur Elise. At the spring recital, a high school senior was scheduled to play the same piece, but she’d back out at the last minute. The recital order was arranged by age with pieces increasing in complexity as the performance continued. I was positioned between two trembling fourth graders. As I began playing, I heard gasps from the audience. At the close of the piece, I received thunderous applause, but I leapt from the piano bench, shutting the lid over the piano keys. In the darkened stairwell, my teacher prompted me to return to the audience for a bow, but I refused. My eyes burned with tears and I couldn’t face the cheers and applause. I had moved with grace for the first time in my life.

Within months the music stopped. My neck ached as I hunched over the keys. Though my fingers played with deft precision, I could no longer sit comfortably at the
piano. My playing subsided and I shocked my mother with my refusal to take more lessons. She’d urge me to sit and play a piece, but I’d mumble about homework or an urgent phone call to a friend. In time, the keys became covered with dust, and the strings out of tune. But whenever I was alone, I would sit at the piano and play a few bars of music.

At church my unusual posture was obvious. My mother would tap my back, urging me to sit back in the pew, but I’d always sit perched at the edge of the seat. As the pastor urged the parishioners to bow their heads in prayer, I’d stare at the uniform bowing of heads. I’d rub my fingers over the tight muscles of my neck and wonder why I was so different.

During a sixth grade orchestra practice, a girl traced her eyes up and down my torso.

“When was your car accident?” she asked.

I ignored her question and pretended to be preoccupied with tightening the strings of my bow. I couldn’t concentrate during the rest of the practice. In the chrome of my music stand I studied my reflection. I attempted to ease my head toward my chest, but I discovered it was mysteriously locked in place like bone meeting bone.

Again, little answers were available at my doctor appointments. I remember the cool hardness of a plastic protractor pinned against my neck and a doctor reciting the degree of my limiting flexibility into a hand held tape recorder. My arms were carefully examined as well. They remained frozen in a semi-flexed position like a
cowboy poised to withdraw his guns from a holster. Once again the protractor was aligned with my limbs, but no explanation was offered.

Physical therapy was strongly encouraged by my doctors. I attended physical therapy three mornings a week before school. Lying on a cot, a physical therapist would attempt to stretch my muscles, but within a few visits, I'd hear her irritated sighs.

"You're not doing your exercises," she said.

I completed my exercises every evening. My bedroom wall was stained with two palm prints from where I'd leaned, stretching the tight muscles of my Achilles tendons.

She shook her head.

"You have repressed anger," she insisted.

She squeezed the tight muscles of my neck and spine.

"You've caused this to happen to yourself."

*   *   *

At the age of fifteen, several weeks before scoliosis surgery, I went shopping with my mother. We had to purchase necessities for my hospital stay, and I slowly ambled through the mall, my breath stifled by my advancing curvature. As we sat for a rest, I caught sight of a store window. Silk pastel gowns and short sequined dresses gleamed under a set of spotlights. Though I was too far away to hear their words, I could sense the excitement of the young girls shopping in the store.
As my mother finished eating, I wandered on my own for a few minutes. Inside the store, I selected a short, black velvet dress with scalloped trim. I held the dress over my clothes and stood before the store’s three way mirror. I knew I would never wear the dress, but I wanted to try it for just a few moments.

I stood before the store’s jewelry display case, the counter meeting me at waist height.

“I want to try this on,” I said as I held the dress beside me.

A woman behind the counter approached me with a tape measure.

“We’ll need to check your size first,” she said.

“I already know,” I said. “I’m 32.24.28.”

“You must mean your waist is twenty-eight inches,” she said.

“No, my hips,” I insisted.

“There’s no such thing as twenty-eight inch hips.”

She turned and laughed with the store clerk beside her.

“Do you know what I’d give to have a twenty-eight inch waist.”

She eyed me from across the countertop. From the waist up I appeared as any other fifteen year old girl with a full face, ample breadth of shoulders, and subtle breasts. She circled the counter and stood beside me and wrapped the tape measure about my body.

“32.24.28. I don’t believe it,” she said as her eyes moved up and down my frame.
My shopping bag lay open on the floor beside me to reveal my new robe and
slippers and latch hook kit. I quickly closed it shut and followed the woman to the
dressing rooms.

Once inside I changed into the gown, mentally transforming the store’s harsh
fluorescent lighting into the dim aura of a high school dance. The door latch wouldn’t
secure. I tried to push it closed several times, but finally I gave up and left a two inch
crack in the door. I could hear the laughter of two girls trying on dresses in the
neighboring stall. I leaned against the wall and closed my eyes, pretending we were
standing about a punch bowl, giggling and sharing gossip. As I tugged the dress over
my head, I heard a gasp from behind. I turned to see a startled store clerk’s face
through the crack in the door.

“My God, what hap- -” she said.

As I turned to face her, she stared toward the floor.

“Do you need another size?” she finally asked.

“No.”

I heard the quick shuffle of her feet depart from the room. As I stood before
the mirror, my reverie was shattered. I could no longer trick myself, even for a few
moments. I stroked my fingers over the prominent contours of my hips, flush beneath
my skin like the rim of a porcelain bowl.

I kept the dress in a box under my bed. Alone at home, I would try it on,
securing the loose spaghetti strap on my slumped shoulder with a piece of scotch tape.
Sitting atop the bathroom vanity I would stare at the reflection of myself, pondering
what others see when they look at me. My loss of body definition followed a
directional path. I resembled a cartoon drawing brought to life by a wave of fairy
dust. At first my face and shoulders appeared, then the beginnings of my torso, but as
if interrupted by evil, the life force departed from my body as quickly as it arrived,
leaving a mirage of what I might have been as the rest of my body transformed to a
whisper.

Nearly forty pounds underweight, I looped a tape measure about my body
imaging what I may have looked like with a normally proportioned body. Translated
into limbs, my loss was as great as the loss of an arm and two legs, and much more
readily identifiable to curious on-lookers. The enigma of me would always be my
greatest loss.

I heard my family arriving through the front door. The bathroom was located
at the top of the stairs, so I knew there was no chance to dart back to my room
unnoticed. I was embarrassed to be seen in my dress, so I stepped inside the bath tub,
just before my sister opened the door.

As I lay in the empty tub basin, I hugged my arms against my body to silence
the rustle of crinoline. Peering around the shower door, I saw my sister stare at the hot
rollers and cosmetics covering the counter top, before sliding them out of place, and
resting her gym bag on the counter top. She leaned over, running a brush through her
long amber curls, than thrust herself upright once again in a single effortless swoop.
She moved with the grace of a marine creature surfacing from a dive. I eyed her well
toned calves, the graceful arch of her spine, and the purposeful motions of her arms
and legs. In that moment, I hated her.
At the age of eighteen, my child-like hips barely spanned half the width of a movie theater seat. I’d sit low in the seat, pressing my knees against the corners of the seat to hold it down. As I turned to reach for popcorn, my leg would sometimes slide and the chair would fold shut again, squishing my body within the seat. I pretended it was a purposeful joke and laughed with my friends, but secretly, I knew that I didn’t weigh enough to hold the seat in place.

It was in a movie theater that I first gazed upon a reflection of my life. As I watched the film, Interview With A Vampire, I sensed an eerie resemblance between myself and the child vampire, Claudia. Though Claudia had been immortalized by the bite of a vampire, she was forever destined to remain in the body of a ten year old child. In one scene, she sketches a nude drawing of a woman, a body she’d imagined for herself.

"Why can’t I change like everyone else?” she lamented.

I felt the hairs on the back of my neck stand up as I realized these were the same words I had silently pondered for years. I tugged my shirt sleeve up over my elbow, and stared at my bony arm in the dim light of the theater. The contour of my upper arm bone was clearly visible beneath my skin. Cupping my fingers about my upper arm I realized my thumb and middle finger met with room to spare.

I kept my observations to myself. By the close of high school I was growing more and more concerned and preoccupied by my unusual appearance, and I dressed
in a manner that camouflaged my body. I had never met another person with muscular
dystrophy, so I assumed that my emaciated body was due to a lack of muscle tone.

In my freshman year of college, I became a wallflower by necessity. I’d attend
parties with friends, but I’d always linger at the periphery of the room, leaning against
doorframes and grasping a hold of banisters for balance. I knew this was supposed to
be the time of my life, but I felt completely out of place.

On one occasion, a first floor rest room was out of service, and I reluctantly
climbed a winding stairwell to the second floor. A line of girls had formed along each
step and I stood at the end of the line, watching a young man on the landing. He was
the type of guy I despised—unbridled testosterone set in motion by the downing of a
six pack.

“I want a girl to hug,” he beckoned in a slow, drunken drawl.

Two girls stepped out of line, but he motioned for them to get back in line.

“I want her,” he said as he pointed in my direction.

The girl beside me stepped toward him, but he shook his head.

“I want the pretty one.”

Sober, I would never have accepted the invitation, but in a haze of alcohol, I
climbed the steps and tucked my head against his chest. I’d never been held in the
arms of a man until now. I’d never imagined a body could feel so strong and solid.
As he slowly rocked me back and forth, I felt his hand slide from the nape of my neck,
then settle over the crook of my arm. Then, he pushed me away abruptly.

“What the hell is wrong with you?”
My lip quivered and I stood motionless. The winding stairs swum below me like a spinning wind chime. He thrust the sleeve of my shirt up over my shoulder. In the dim light, my emaciated arm appeared ghostly white.

"Are you anorexic?"

"No!"

"Are you on drugs?"

The women on the stairs offered no help. Only their eyes peered from the darkness. I ducked around him and slipped down the stairs as quickly as I could.

* * *

The summer before I began graduate school in English at Iowa State University, I battled my weight with a vengeance. I kept journal entries of my caloric intake and forced myself to eat high fatty foods I despised. Each week I weighed myself, but my weight never fluctuated.

At the age of twenty-five, a new worry had entered my mind. Many of my friends had begun families, and I felt intensely left out. I realized my body wore a blinking neon sign of infertility. I worried at my chances of marriage, of a successful life with a husband and family. I thought of this as I sat in my car behind the local drug store and drank Sustacal Plus. My stomach heaved at the gritty shake, but I gulped down the contents anyway. The directions suggested one can a day, but I wanted results. Instead of the one recommended can, I drank six. I kept this ritual for only three days.
At the age of twenty-six I visited a podiatrist for the first time. Though I hadn’t encountered any serious problems with my feet, I worried that my waddling gait might present problems in the future. At the close of the appointment, my doctor spoke casually to me as she put away her supplies. As she looked back toward my x-ray she stopped abruptly in mid-sentence and gasped. Immediately, I felt a sense of unease. I’d always associated doctors with tact and reservation and her candid outburst surprised me. I stared at my feet. Was I growing an extra toe? Did I have osteoporosis?

“How old are you?” she questioned.

She stepped toward my x-ray and strummed her finger over the name plate in the corner. My name and birth date were clearly visible.

“Twenty-six.”

Her brow furrowed and she stoked her finger beneath her chin.

“This just can’t be,” she said as she shook her head. “I’ve never seen this before. I’ve never read of anything like this.”

I leaned forward in my seat, tucking my feet beneath my legs.

“What is it?”

“Do you see these lines on each of the long bones in your foot?”
From a distance I could make out a set of lines on each of the five bones. They were grainy and difficult to see. A mere millimeter space separated one line from the other.

"These are your growth plates," she explained as I crossed the room and stared intently at the x-ray.

"These lines are never visible in an adult patient. They close before the onset of menstruation."

"What does this mean?" I asked.

She crossed her arms across her chest and leaned against the wall.

"Your body laid out a scaffolding of your growth, but you never filled in this gap."

My eyes narrowed and I hugged my knees against my chest. As I softly rocked back and forth, the puckered waistline of my size zero jeans rubbed against my lower back.

"This is an x-ray of a child's foot," she said.

"What about a dwarf? Surely you'd see an x-ray like this?"

She shook her head.

"In a person of short stature the growth plates will close."

My head began to throb, but I felt simultaneously relieved. For years I'd been desperate for answers, and now we'd finally discovered something.

"Essentially, your body stopped growing. This is a record of when this took place."
I imagined myself as a tree in a forest. Though planted at the same time as the trees that surround me, I lacked many of my annual rings.

"I'll have one of my medical interns run a literature search, but I'm certain this has never been reported previously."

As I drove home in the car, I found my eyes watering. I pulled to the side of Polk Boulevard, the stately tree-lined thoroughfare passing in front of my high school. In the distance, I saw students running across the front lawn. I envied their strong command of their bodies, the confident stride of their steps. I never had this, I realized. Though I wore a bright smile each day of high school, on the inside, I was desperately alone and afraid. I always stood at the periphery, watching others but never fully integrated, even into my own body.

At home, I tried on a pair of pantyhose. Though I’d worn panty hose many times previously, this time I stared intently at my shape. I stretched my legs out before me and studied the dense fibers of the nylon. They were barely stretched by my legs, but rather they hung limply like the scrunched like the shrunken print of a deflated balloon. As I glanced at the chart of the pantyhose package, I realized I was an uncharted point on the grid- -5’3", 87 pounds. For more than a decade, my weight had not wavered. The weight of a ten year old child, I reminded myself.

I laid photographs of myself at various ages across my bureau. Standing before the mirror, I held each photo beside my arm and leg, scrutinizing the contours of my limbs. In one photo taken in 1985, I stood alongside my brother and sister on the first day of school. I saw the bony protuberance of my elbow, and the missing
flesh of my biceps. As I held the photograph alongside my arm, I realized the
unmistakable resemblance. It was the same arm.

Sifting through my scrap books, a letter fell into my lap. As I skimmed the
contents, I was instantly transported back to the age of eighteen. I’d remembered
writing a letter to my friend Suzy as we left for college. At the time I’d considered my
observations melodramatic, but now the words spoke with haunting resonance.

_August 10, 1993_

_I feel as if I always remained a child. I’ve watched everyone grow up around
me, but I have always stayed the same. Aside from the development of breasts, I’ve
never considered myself a woman. I don’t know where I belong in this world. I don’t
know who I am._

When my mother arrived home, she immediately recognized the far away look
in my eyes.

“Did I ever change?”

She offered a puzzled glance as she began to unload sacks of groceries.

“I don’t understand.”

I told her about the x-ray. Then, I raised my ankle length skirt to the middle of
my thighs.

“Look at my legs. These are the same legs I had when I was ten, aren’t they?”

She paused for a moment, pondering my tiny silhouette. Moments later she
crossed the room and held me.
“No, you never changed,” she whispered in my ear.
I think about this person living far away, yet in a strange way, inhabiting the same body as mine. I wonder what she does for a living, who she loves and what her family is like, but, most of all, I long to meet her someday. I imagine traveling to a small café in a distant country and out of the crowd of bustling patrons, eyeing someone with the same waddling gait as myself. Oblivious to the passage of time, I would speak endlessly to her like a woman reunited with a child given up for adoption.

- Johns Hopkins Magazine, November 2000

I sent my message in a bottle with little hope of a reply. I'd wanted more than anything to meet someone like myself, but this was a dream I never imagined would come true. Then, one evening, in the summer of 2001, my world changed forever.

"It's me. It's Mary," replies the cheery voice on the other end of the phone.

I cup the receiver against my ear and listened intently as Mary describes her symptoms of Emery-Dreifuss muscular dystrophy. For the most part, we are nearly an identical match. We share the same stiffened upper torso, the frozen elbow joint locked in a flexed position, and the same curious waddle.

"I thought I was the only one. All my life I was told I was the only woman in the U.S. with this disease."

"Me too," I say.

"I never thought I'd live to talk to someone who looks like me," says Mary.
My body tenses as I listen as Mary describes her numerous surgeries including a cardiac transplant at the age of twenty-four. Though I know cardiac problems requiring transplantation are rare with this condition, I feel a nervous rumbling of my stomach and a strong sense of empathy as I realize we share so much in common. Within minutes we laugh with one another with the ease of two friends who’ve shared a lifetime of memories.

We talk for nearly an hour that first night, neither of us wanting to end the conversation. At night I imagine the face that accompanies her words. For the first time in my life, I no longer feel alone.

* * *

I know I am being watched and scrutinized, but on this day, things are different. For the first time in my life, I do not hear the furious scribblings of ink pens as I walk for a row of observers. As I continue my stride, my back to my onlookers, my lips curl into a broad smile. Behind me I hear the hum of conversation and the whir of a motorized scooter. Turning to face forward, I see the warm friendly smiles of friends I feel I have known for a lifetime.

“That’s the walk, Mary,” purrs Mary’s husband Terry as he strokes his chin with his hand. “That’s just how you looked when you walked down the aisle.”

Mary leans forward draping her arms over the shiny chrome of her scooter controls. She smiles in my direction.
“I hate video cameras,” she explains. “I have no idea what I look like when I walk.”

We share the same avoidance of the video camera lens. When confronted with a camera, we both freeze in place, like a vulnerable animal silenced by the roving eyes of a predator. Few images of me in motion exist on film.

In contrast to our fears of observing our own selves in motion, Mary and I eye one another’s movements closely. We are mirror images of one another—myself, an image of Mary twelve years past, and she, a reflection of my life twelve years into the future. Our bodies have been changed from the rest of the world, yet this is the connection that has drawn us together. This is the first time either of us has gazed upon another woman with Emery-Dreifuss muscular dystrophy.

Within minutes, the large garage owned by Mary’s in-laws begins to fill with family and friends. They smile affectionately in my direction and watch me closely as I move about the room.

“Why look, it’s a little, Mary,” proclaims one guest.

I grow tired as I stand. Instinctively, I slide my palms into the back pockets of my jeans and lock my thumbs in the belt loops. This subtle shift in posture shifts the bulk of my body weight off of my legs. Mary’s friend, Karlene walks over to my side, shaking her head and smiling. She eyes the back of my jeans and notes the overly worn pockets and frayed belt loops.

“Mary used to stand just like that,” she says.
From the far corner of the garage, the smell of seared pork and portobella mushrooms fills the room. Mary’s husband, Terry, cooks in a makeshift kitchen in the corner of the garage. From among the tools on the wall and the cans of motor oil and spare screws and nails, he draws tiny canisters of spices. He seasons the food and checks it for taste before presenting plates of food to his dinner guests.

I take a seat in an old faded recliner alongside Mary’s scooter. Her face beams with excitement. Mary’s long blonde hair is styled in thick golden curls that fall to the center of her back. Even as her muscle weakness progresses, I know that she spends hours each morning getting ready. She lingers in the tub for long, relaxing bubble baths, and carefully strokes her make up across her face. Though Mary is the most beautiful woman I have ever seen, I don’t consider her vain. I cherish the way she cares for her appearance, even as her heart fades within her chest.

As Mary departs early to get ready for bed, I remain behind in the garage talking with Karlene. She shares her favorite memories of Mary in between soft puffs of her cigarette. She speaks with a fondness I’ve only seen expressed by a parent of a small child.

Soon, Terry rejoins us, and I gladly accept the offer to hold onto his arm as I cross the garage.

“I know you want me to hold my arm high--just like this,” he says as I grasp his forearm just below the elbow.

By our mid-twenties, both Mary and I developed the tendency to grasp a hold a person’s forearm when walking. It’s done partly for balance, and partly to ease the
throb of weakened muscles. A cane or walker is positioned to low, but a forearm meets at just the right height.

As we reach the doorway of the garage, I stop in place. Though a drop off of only a couple inches exists on the opposite side, I extend my right foot before and tap three times before stepping through the doorframe.

“Karlene, watch what she’s doing,” beckons Terry.

“Mary used to the same thing in that exact same spot,” Karlene explains.

The muscle weakness throughout the body of an Emery-Dreifuss patient, is a mosaic of strong muscles alongside weakened muscles. An MRI of an affected leg displays the same unusual pattern in patients throughout the world. Overtime, our bodies have adapted in the same ways at nearly the same point in development.

Terry leans against my car, folding his arms across his chest and nodding toward his home, kitty corner to his parents’ home.

“I know what you’re thinking about right now,” says Terry. “You’re worried about tripping on the sticks on the sidewalk. You’re already plotting your path around the pot hole in the drive. But most of all, I know you’re eyeing those three steps and thinking about how you don’t want to climb them.”

“Exactly,” I say as I laugh.

“But when you come for a visit, you don’t have to worry about that anymore.”

Terry secures my arm about his neck, and in a single motion, he picks me up from the ground.

“Remember, I’ve done this only about a million times.”
An unsteady walk that would have taken minutes, passes in a matter of seconds. I watch the ground spin beneath us, a haze of brown and green. His steady steps crush sticks and bend the grass.

Inside, I peer over Terry’s shoulder. The living room is dim and unoccupied. A pair of shoes rests idly in the corner. A jacket is draped over a folding chair, the room’s solitary piece of furniture. The central corridor of the house is ablaze with light and sound. As Mary’s ability to walk became impeded over the years, walls were removed, and extra doors installed to secure the fewest steps to any destination. Over time, even the walls of the small white bungalow seem to wrap about the spirit in its central bedroom.

Mary is already dressed for bed. She wears a long, silk nightgown, and a cotton cardigan. She sits like a Barbie doll upon the mattresses. Her long legs stick straight out before her and she sits straight up without reclining into the pillows behind her. As Terry sets me in the bed beside her, I naturally assume the same posture.

“I just can’t get over the way you both sit like that,” says Karlene as she shakes her head. “Doesn’t that hurt your legs?”

Kelsey climbs across the bed with the eagerness of a young child seeking sanctuary from a thunderstorm. She burrows her face in the crook of Mary’s arm and speaks softly of the day’s events at school. The ice clinks in Karlene’s glass, and she steps just outside the bedroom doorframe before lighting a second cigarette. Kelsey’s back remains turned toward me for the duration of the conversation.

“You’re such a pretty girl,” says Mary as she runs her fingers through Kelsey’s silky blonde bob.
Their relationship is unlike any mother-daughter pair I have known before. Among company, many mothers would briskly brush aside their daughters concerns and suggest a time in private to speak. In the midst of a bustling ER and against the backdrop of the whir of ambulance sirens, they have developed the ability to block out the sights and sounds around them, securing moments of serenity in the midst of chaos.

After Kelsey leaves for bed, I scan Mary and Terry’s wedding album.

“This is actually the renewal of our vows ten years later,” Mary explains.

I’m thoroughly impressed. The pictures include all the flair of an original wedding. Mary is pictured in her wedding gown, and Terry in a tuxedo. Five groomsmen and five bridesmaid stand beside them before a white gazebo.

“She got all of you back in your original bridesmaid dresses?” I ask incredulously.

“We sure love Mary,” replies Karlene.

Mary had a heart transplant in 1988 at the age of twenty-four. Though doctors cautioned that she would most like only survive five years, she surprised even herself when she reached her tenth wedding anniversary.

“Girl, we have got to get you married,” says Karlene.

She takes a long, slow drag on her cigarette and smiles in my direction. For a moment I feel unnerved, but I realize she is only concerned about me. Karlene has been taking care of Mary longer than I’ve been alive. She knows what lies in my future and I trust her more than I trust my own doctors.
“Oh, Karlene. She’s going to meet someone in the fall,” says Mary without hesitation.

As I prepare for bed, Karlene passes before the open bathroom doorway and cups her hand over her mouth in surprise.

“Terry, come here. You’ve got to see this,” she says as she beckons for him to join her in the doorway.

I’m embarrassed that she’s discovered me seated on the porcelain of Mary and Terry’s sink, my legs dangling inches from the ground. I’m company in their home, and I should show more respect to their belongings, but the habit is so instinctive that I don’t realize what I am doing. Over the years, I’d adapted this simple trick as my legs grew too weak to stand for minutes at a time.

“This is just how Mary brushes her teeth,” explains Terry with a smile.

As I lie in bed beside Mary, I realize what it must feel like to sleep beside me at night. Due to our weakened muscles, we both over-exaggerate our rolls to one side or the other. I laugh to myself as I sense Mary’s exuberant flailing of limbs like the thrashing of a fish cast upon shore. I know I will move in the same manner as I fall asleep in just a few moments.

“I’m so cold,” she laments.

Mary begins to snore softly and I realize she has spoken out in deep slumber. To my embarrassment, I realize I have curled into a ball at the far corner of the mattress, taking the covers with me. As I drape the sheets and blankets double-
across her body, my hand grazes her leg. I sense the same chill as a palm grasping a metal door knob on a frozen January morning. She’d described the coldness of her limbs, a consequence of heart failure, but I’d never understood the reality, until I’d brushed against her. Strained gasps of air escape her lips. Her breath is labored and guttural. I lie close to Mary. Our intertwined hair pools into a wreath above our heads. I study the rise and full of her chest until we breathe in unison.

“I love you, Mary,” I whisper.

* * *

“Good morning, Mary.”

Sunlight streams through the curtains. The shadow of Terry kneeling beside the bed climbs the bedroom wall. In the distance, I hear the soft crash of water filling a tub basin. I lie motionless as if I am asleep.

Inches away, a model of my future self shifts upon the mattress. I resist the urge to turn over, but instead I gauge Mary’s strength as she stirs beside me.

Terry leaves for work and Mary continues her bath. I get dressed and lie back on the bed, tempted to fall asleep again as an hour and twenty minutes pass by. In the back of the house, I hear the soft taps of her walking stick as Mary emerges unassisted from the bathroom. I long to know how she walks, how I will someday walk, but I remain on the bed, and watch through a crack in the bedroom door.
Mary was worried that I would be upset to learn how she must move, to learn how the increasing muscle weakness has affected her, and how it will affect me in the future. Instead I feel a sense of relief as I gauge how she moves about her house. She can bathe and dress independently at the age of 39, and this is a tremendous reassurance to me.

Eventually, I join Mary in the kitchen. As I pull a stool alongside her, she extends her walking stick in my direction.

I shake my head.

"I don't want it."

I’m fearful of Mary’s dependence on her walking stick. I know she cannot take a single step without it. Seven years ago, the kitchen countertops failed to provide sufficient support and she’d reached for her broom handle. She’d learned to take slow, steady pivots as if braced against a pogo stick that never left the ground. Returning from work one day, Terry watched Mary moving about the kitchen, broomstick in hand. He crafted a walking stick for Mary and she’s used it ever since. Over time, the harsh lines of the chiseled wood were softened by the touch of Mary. This simple stick represents their love for one another, the blending of their worlds. In the years that followed Kelsey would stand with outstretched arms, beckoning her mother to take just one single step without the stick, but she never did.

I attempt to rest the stick against the countertop, but Mary cups my hands about it and stares intently into my eyes.

"I need to see you try."
Grasping the stick haphazardly, I position it far from my body as a shepherd yields a staff. My outstretched arm quivers as my sweaty palm slides over the smooth chiseled wood. I offer her a bewildered look.

“Like this,” insists Mary as she prompts me to weave my fingers together.

I hold the stick close to my body and take in the tender scent of Mary’s lotions and bath salts. Wrapping my interlocked fingers over the smooth round bulb, my fingers settle into the shallow grooves, still warm from Mary’s grasp.

Now the soft taps emanate from me. In a few moments I will once again cast this stick far from me, but years later, I know I will reach for it.

“When will I need this?” I ask.

“Thirty-two. Things will change when you’re thirty-two.”

“I was worried that maybe... well maybe you’d be upset when you saw the way I get around,” she suggests.

Mary is a representation of what lies in my future. As we compare stories, I realize our bodies have weakened at nearly the same rate. We both worked at fast food restaurants at the age of fourteen, served as cashiers in our late teen years, and we both lost the ability to rise unassisted from the ground sometime around the age of eighteen.

“I’m not upset. I promise,” I reply.

Mary shines with the radiant smile of a new parent. There is much to learn and much to overcome, but she knows the promise of the future lies in these first tedious steps. The moments of my first steps are lost to the innocence of youth, but now I
celebrate a memory all the more precious. The legacy of her survival has been passed on. I have learned to un-walk.

Mary leans forward in her seat straining to watch a wren bobbing on a limb alongside her kitchen window.

“You understand why Kelsey’s graduation is so important to me.”

Her gaze remains fixed upon the window. My mouth grows dry and I lean toward the stick strumming the bulb against my cheek. I remember lengthy telephone conversations about upswept hairstyles and silk gowns, dyed to match pumps and beaded hand bags. I recognized urgency in her voice. This was the goodbye she could plan. The one she could rehearse over and over in her mind.

“I know I won’t see her graduate from high school.”

“Don’t talk like that, Mary,” I insist as I draw a stool beside her. “You’re going to get a new heart and everything will be alright-”

I pause in mid sentence. Mary’s face is that of new fallen snow. Tiny creases line the corners of her eyes and the nape of her lips like a settling twig disturbing a pristine landscape. She is stoic and serene.

“I have my heart,” she says as she strokes the thin scar just visible above her v-neck t-shirt.

In this moment I feel small and inconsiderate. I’m taking the easy way out, I remind myself.

“This is why you celebrated your wedding a second time?”

As I gaze toward the kitchen window, the sparkle of Christmas ornaments catches my eye. I see last season’s gift to Mary dancing among them—a wooden
spool painted to resemble a snowman. I'd imagined she'd store the ornament out of sight, taking it out only once a year to adorn a tree, but now I understand its omniscient presence. Mary's life is a simultaneous celebration of seasons.

"Mostly, I worry about Karlene," she says.

The front door creaks and I hear the footsteps of Terry entering the front foyer. Instantaneously, Mary's expression changes. She clasps the top of my hand. Her voice is hushed, yet urgent.

"Never speak of this in front of Terry. Promise me."

I blink hard three times. Terry's footsteps stop behind my stool. Mary's golden curls gleam as sunshine floods the kitchen window. Her lips curl into an unbridled smile and any hint of worry escapes her beautiful face.

* * *

My phone rings on a Saturday afternoon, twelve weeks after my visit to Mary's. The call interrupts my lunch preparation, and I wring my hands in a towel before picking up a receiver, but the aroma of onion lingers, stinging my eyes and burning my eyes.

"Honey, it's Karlene."

My stomach lurches. I've never received a call from Karlene.

"How's Mary?" I ask in an overly cheery voice.
The connection is quiet for a few moments. Somewhere in Karlene’s home, another receiver is picked up. The dissonant tones of depressed phone keys fills my ears.

“I’m on the phone.”

I imagine Karlene’s palm is cupped over the receiver, but I distinctly hear her words. Her voice is strained and uncharacteristically harsh. The receiver is abruptly replaced.

“Mary passed away last night.”

I can’t begin to describe my feelings at this moment. I listen numbly as Karlene described Mary’s passing during a surgery to implant a temporary cardiac pump.

“What was the last thing she said,” I ask.

Karlene’s pauses for a few moments and when she speaks, her voice is shaky.

“She was alone with Terry. She just wanted him to promise that she’d be OK.”

We remain silent again, pondering the gravity of this statement.

“He told her the truth,” I finally offer. “People enter heaven in different ways. Some people are abandoned, others are abused. He carried Mary there.”

“I know,” says Karlene.

For the next two days, I prepare the same lunch, bathing my hands in the pungent scent of green peppers and onions. If I don’t, I remind myself, I’ll forever associate these smells with the loss of Mary. Soon the smell lingers on my skin and wafts from my sheets and towels. I stop cutting green peppers and onions.
As I park alongside the funeral home, I immediately sense the significance of this event. Young people are gathered on the front porch and the crowd spills out onto the lawn. I stare at the ground as I walk and try to squelch the burning tears in the corners of my eyes.

Before I reach the front door, I feel the warm hug of Karlene. She offers her arm and I walk with one hand clutching Karlene, and the other, my mother. As we enter the foyer I'm comforted by the site of a large easel displaying photos of Mary.

My eyes rove a photo of Mary’s sixth grade graduation class. Standing shoulder to shoulder, clad in short seventies style dresses, the young girls blend one into another. All of the girls, except one, sport platform shoes with large chunky heels. Immediately, my eyes lock on one figure. I smooth my finger over the photo, tracing the slender lines of a pair of black leather boots. They extend to mid-calf, revealing only a couple inches of leg below the hemline.

“This is Mary,” I say without hesitation.

Karlene nods.

“She was always upset that she was too skinny. She used to try to hide herself,” says Karlene.

In our phone conversations, Mary had empathized with my slight build. Until the age of 24, her weight had remained at only ninety pounds, despite a 5’7” frame. Following her pregnancy and heart transplant, Mary had gained nearly thirty pounds. She appeared healthy and energetic in her later photos, even as her heart was failing.
One by one, group photos, pass before my eyes. I see Mary standing amongst friends on the steps of her grade school, and posing with the cast of a drama presentation. Though I’ve never seen photos of Mary’s childhood, in a matter of seconds, I can draw her out of crowed. As I scan the photos, I spot the subtle difference of her posture among dozens of students. Her peers stand military style, arms straight against sides, the soles of shoes side by side, heels cocked together. In each snapshot, Mary is pictured with one shoe positioned slightly ahead of the other. She braces her palms against the small of her back, shifting the weight of her stance away from her miniature calves.

I sense the overwhelming love for Mary as we continue through the funeral home. Karlene tells me that more than 400 people have already visited. I sense the eyes of others eyeing my gait, but I feel warmth and comfort.

“I love to watch you walk,” says Mary’s step daughter, Aja.

In a corner room Kelsey sits with a friend. The room is dark except for the soft glow of a table side lamp. As Karlene beckons her she crosses the room and stands with her arms tightly crossed against her chest. She stares at a point on the wall behind me, and I resist the urge to give her a hug. Wordlessly she returns to her seat on the sofa.

Reluctantly I walk toward Mary’s casket. My mother and Karlene offer a gentle squeeze. As I look inside, my turbulent emotions subside. I don’t see Mary there. The form in front of me appears plastic. Out of the corner of my eye, I see two
more easels of photos celebrating Mary’s life. I feel myself drawn away from the casket and toward these pictures.

Terry and his twenty year old son, Dustin stand beside the casket.

“Doesn’t this look familiar?” he says to Dustin as he gestures to my legs.

Terry and Dustin hug me and my mother and we stand silently in front of Mary’s casket.

“I saw a shooting star in the sky the night Mary died. I took it as I sign. I knew she was alright when I saw that,” says Terry.

As I turn away from the casket, I see Mary’s scooter and walking stick in the far corner of the room. Mary lies as any other person in a casket. There is no hint of her muscle weakness. In this moment, I realize I will live and die just as Mary did. Thoughts of a miracle cure, or a medical advance that will significantly change my life disappear from my psyche forever. As I return home, I will store research articles out of sight. I’ll search the web for research updates much less frequently. Instead, I’ll learn to take more pictures.

As I continue to study the photos, I discover my favorite photo of Mary. Shortly after their relationship began, Mary and Terry are pictured alongside Terry’s motorcycle. To counter the mid-summer heat, the sleeves of Mary’s black t-shirt are rolled to the shoulder revealing the once-hidden contours of her tiny arms. She appears confident and happy and full of life. She cocks her head back slightly as Terry leans down to kiss her.

“This is when Mary became beautiful,” I say to Karlene as I point to the photo.