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Monster Love

A Thesis submitted in partial satisfaction
of the requirements for the degree of

Master of Fine Arts

in

Creative Writing and Writing for the Performing Arts

by

Courtney Lund

June 2014

Thesis Committee:
Professor Mike Davis, Chairperson
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The Thesis of Courtney Lund is approved:

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University of California, Riverside

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*For
God and Gavin*



ABSTRACT OF THE THESIS

Monster Love

by

Courtney Lund

Master of Fine Arts, Graduate Program in Creative Writing and Writing for the
Performing Arts
University of California, Riverside, June 2014
Professor Mike Davis, Chairperson

The pages that follow are the beginning excerpts from my memoir, *Monster Love*, a moving account of my journey through a family member's rare terminal illness. At four months old my little brother, Gavin, was put in Hospice care and given a year to live. *Monster Love* follows the fearful months that follow, performing a sprint to answer the question that torments me: what does it mean to love a dying baby? The book offers up an inspiring answer to that question. Throughout all obstacles, the bond a family shares can beat almost anything life throws at them. For love does indeed conquer all.

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Part One: The Call

I.

Mom had been so busy with Gavin; I couldn't remember the last time we talked about anything "normal." I didn't want to answer her phone call. But I had to. It was family.

"Hello?"

To my surprise it was Dad's voice muffled on the other end of the line. He barely got the words out, "Hey, Pokey, do you have time to talk? It's about Gavin."

"No. Not really. I have class soon," I said. "I'm finishing up my Spanish homework before class at one." I felt the sweat begin to build up on the ends of my fingertips.

A silence, and a snuffle came from the opposite end.

"Is Gavin okay?"

"We got a CT scan back from the doctors today."

"And?"

"Gavin's finally been given a diagnosis."

I thought of August. Painful, foggy, confusing August. Mom and Dad spent three weeks in the hospital. They slept on the floor, in the lobby. Gavin, at six weeks old, had become unimaginably, uncontrollably ill. No doctors in America had a diagnosis for him. Each day he had looked paler and more fragile, the way colic made animals look. Like they were dying.

"It's not just bad Meningitis?"

"No, much worse, Pokey." The tone in Dad's voice changed.

“Gavin’s CT scan showed some calcification growth in his brain.”

“What does that mean?” Sweat now covered my body. There was a pause from the opposite end, a pause that would seem to last a lifetime.

“Gavin has a terminal illness,” Dad spoke quickly, yet slowly, as if he tried to get it out as quick as possible because it wasn’t quite real, but slowly in the sense that this was a big statement. And today was just a normal Thursday.

I pieced together the two words *terminal* and *illness*. An illness that had an end. Synonymous for terminal was fatal. Fatal was death.

Survivors always commented that they saw their lives flash before their eyes when they had experienced an out of body, near death experience. It wasn’t my life I saw, but my brother’s, or the one he wouldn’t get. Images of faceless ghost-like images flooded my brain: of a man in a tux, driving in a car, hugging us, his family.

“What do you mean?”

“Gavin has developed brain damage. It is part of his illness.” Dad spoke softly through the little courage he had left. Mom was listening in. I could hear her stunted cries in the background.

“It’s a scary disease called Aicardi-Goutieres Syndrome,” he continued.

“What? Spell it,” I demanded.

My hands were so sweaty that I could barely hold my pen, and they shook as I tried writing out the disease. The next few minutes my brain grew foggy, like the early

mornings in Imperial Beach, the small beach town where I spent my childhood when I was the only child, when life was simple, easy.

The final words I heard Dad say were, “The doctors have given Gavin one year to live,” he said. “They’re putting him in Hospice care.”

The fog faded. There was blinding clarity.

I let the words linger and ring in my mind. The ringing felt like a fire alarm, a demonic like sting that permeated a lasting migraine. This all must have been a terrible misunderstanding. Hospice was for end of life care. This couldn’t be right. I felt as if I’d been punched in the face; worse, kicked off the planet.

Then another alarm went off inside me, but instead of my head this one was in my heart. The guilt inside me grew ten sizes as I pondered the question that now tormented me, how will I learn to love a dying baby? How could anyone truly? Love, the deepest, most sacred act, that we do out of faith, was going to be stripped from me in under a year.

“I have to go. I’ll call you later,” I said and hung up the phone like it was any other conversation. I looked at the time. It was 12:50.

I skipped my Spanish homework and rode my red beach cruiser to class a little late. I sat in the back of the classroom, and had a blank stare cascade over my face to let the teacher know something was wrong, but don’t bother me about it. I was in shock. All I focused on was the ticking of the clock, yet time felt as if it stood still. Nothing made sense, and my pencil moved across my lined paper out of routine. We were learning *el preterito*.

When the teacher announced class was over I stared at her and smiled like it would be the last. I wanted to tell her everything that just happened. How I sat through an hour of Spanish I was not sure. I was not sure of anything.

I walked out of the building, towards my parked bike among the hundreds in the bike rack. People were laughing, on their phones, the sun was shining. I was no longer a part of them. The way they carried themselves, these ordinary people, with perky chests and happy heads was a world I no longer belonged to. I wondered where I belonged.

I rode my bike to Keg N Bottle, the local liquor store, and bought cigarettes and smoked one on the steps outside of the sorority house. Cigarettes were never my thing, but I felt maybe they could help. Kelly, my best friend in the sorority, joined me for one. She was taking a break from studying for our Oceanography midterm.

“What’s wrong?” she asked. Her blue eyes pierced me, like if she already knew.

My eyes must have given it away. But I couldn’t tell her—not yet. I couldn’t let an entire house of forty girls know there was something wrong with me, and something wrong with my family.

“Nothing,” I replied. I inhaled then started coughing.

Coughing was my cover-up and *Nothing* was my only reasonable response until I was able to muster up a plan to fix this. My mind felt like a melting pot of the strangest ingredients: worms, honey, mud, and ketchup – all melting together. I know that sounded odd, but this was odd. Hell, this was a fastball to the face, a knockout. Life as I had known it was over. And my poor family? How were they? My whole life I had tried to be perfect, make life perfect. I was a planner, and here at school, I had pondered some

serious existential questions, like what was my place in the world? What career path would I choose? This was not part of my plan. In fact, I had no idea what I would do.

I was a fixer. I fixed things. I got in the middle of arguments, I cleaned up the mess, and I was the one who got the free coupon from Good Humor when they forgot the fudgesicles in my mixed variety box of popsicles. I was six and wrote a letter to the company informing them of their mistake and they sent me ten dollars in Good Humor bucks. But how would I fix this? This was big.

Big, shocking news had also come a year ago from today. Only if I had known what was to come I would have treated the situation a little differently.

II.

Over a year earlier I packed up my stuff for college. I remembered the day vividly.

Santa Ana winds blustered in the thick autumn air – a sign change was coming.

Which was a bad thing, because I hated change. I hated it more than I hated cheese, which said a lot because my least favorite food in the entire world was cheese. I hated the way cheese smelled, the slick, plastic texture, and of course, the rancid taste. As a child, Dad, who was the grocery shopper in the family, used to push me through the aisles at the store, while handing me various snacks like donuts, frozen bean burritos to help with my teething or sometimes slices of Kraft American cheese. He said I used to love cheese, tearing through all the individual slices, asking for more. Then one day, Dad handed me some generic brand. I took one bite, spit it out, and never ate cheese again. It left a bad taste in my mouth, sort of like change.

My family tried their best to make the day run smoothly. Dad woke early to prepare breakfast: beautifully cut grapefruit, apples cut into little swans, piping hot Pillsbury cinnamon rolls, and crispy pork sausage. Mom had double-checked my room to see if I'd forgotten anything. Danika and Sydney, my two younger sisters, followed me around like little puppies. The whirlwind of moving out of your parents' home for the first time can be overwhelming. What do I bring? What do I leave behind? The things we choose define us, and this was a new start. College. The word excited and petrified me. I would have to make new friends and begin new hobbies. In high school I consumed myself in varsity sports and AP classes. I would have played water polo, my favorite sport, in college but the competition was unforgiving. UC Santa Barbara, located on the

Pacific Ocean, an hour north of Los Angeles, was a division one school. The athletes were good. Really good. Mom and Dad still hounded me to consider it. Dad swam in college and Mom played field hockey and dove competitively at hers. I, as the first child, was supposed to set the standard. It was an unspoken desire on their part: to have a kid play a college sport. I would not be that child. So Mom offered another idea: Greek Life.

“Joining a sorority opens all kinds of doors for you. Just try it on,” Mom said. She and Dad were my biggest cheerleaders, always inspired me to make the most of things, like college. She said they had this thing called Test Files, where years of past tests and essays were hidden and kept for the use of members only. She said joining one would also offer up a home base, a warm home-cooked meal, and friends.

The final hour before departure I found myself locked in the downstairs bathroom. I needed a moment to reflect. I looked at myself in the mirror, which I often did, although the mirror. I appeared confident. My hair was long and extra blond from the summer rays, I had a light glow to my skin, my body was extra lean. There was this innocence about me yet also this quaint sex appeal. I was like a cross between a light-haired Mary Magdalene and a scholarly Madonna-Whore. However put together I looked on the outside, did not reflect the combustion happening on the inside. I turned on “Dreams” by *The Cranberries* on my new laptop Dad got me for graduation. I sat on the lid of the toilet, quietly wept, thinking *I don't want to go*.

“Honey, are you okay in there?” Mom asked from outside the bathroom.

I paused before answering. After I rubbed my eyes, a piece of art Mom had hanging on the wall came into focus. In cursive writing the canvas read – *Home is where*

your story begins. This was my new beginning, the time to write my story, to let go of the fear of change. That's what I'd like to have thought.

"I'm coming in." The door creaked open and Mom sat down next to me. Her skin was olive colored, draped with silky, dirty blond hair. She had one of those beauty marks like Marilyn Monroe had, over her top lip. She was a natural beauty, who didn't believe in designer brands. She believed wealth came from an inward place. She never wore an ounce of make-up, loved adventure, gardening, and animals. She believed in God, and being kind. She was a wholesome, humble, inspiring human being. And incredibly smart, she was a family doctor. I wondered if I'd ever aspire to be someone like her. She rubbed my back in comforting circular motions.

"What's wrong, sweetie? Are you going to miss Sasha?" she asked. Mom spoke in a sturdy-smooth voice. She was a strong woman, rarely showing signs of weakness. In the "olden days," as we called them, she could have been pegged as having traits of a man's personality. Or in modern times, someone might call her a feminist, though she would never call herself one. It was too extreme, and my mother believed in moderation.

I laughed. Sasha, my beagle, was the brunt of most of Mom and Dad's animal jokes. She was the only animal besides the horses we spent over five dollars on and sadly the biggest pain. Food drove her head and heart. One time Mom caught her on top of the stove eating sizzling hot lumpia out of the pan. She charred her snout in hot oil but didn't care because *hello*, it was lumpia. Her howl was unrelenting. I received her for Christmas in seventh grade. We had moved schools and towns to "get out of the ghetto before it was too late." Those were Mom's words. She, unlike Dad, who did not grow-up in a lower

working class neighborhood, had a keen sense for when a neighborhood was no longer safe. When I was very young, I remember outlining my finger over a small hole in the window, from where a bullet sliced through from a bunch of gang bangers in the middle of the night.

We moved from a poor beach town north of the Tijuana border to Bonita, a northern San Diego suburb. In Spanish, *bonita* meant beautiful. Fitting for Sasha who was also *bonita* – with her cream-colored coat and glossy green eyes. Mom said Sasha was my reward for straight A’s in seventh grade, although looking back; it had to be slightly out of guilt. According to Mom I spent afternoons wailing in my upstairs bedroom, “I hate this house. I have no friends. I hate this house!” I was also, like, 13 and acne-faced and hadn’t lost my baby fat. I wore Eeyore overalls and over-sized sweatshirts to hide my boobs. Sasha, would be my *hoo-ha*, which Mom termed as *joy*.

“No Mom. I don’t want to go. I don’t know anyone.” I knew I was being a brat, letting Mom baby me, but hey, I was milking the last I could get before I’d be off on my own.

“Oh, honey. You will make friends. You always do!” she said.

I sighed in response. She was right. I had that same knack she and Dad had: the ability to talk to and be friends with anyone. She hugged me and took strands of tear-drenched hair out of my eyes and slipped them behind my ear.

When I finally decided to move my way over to the Suburban packed to go, Sydney asked, “Mommy, what’s wrong with Courtney?” Mom replied, “She’s just going to miss us is all,” with a smile that made me want to melt to the ground right there.

Sydney hugged me goodbye. Danika joined her. Their little arms wrapped tight around my core, as if anchoring me to stay. Danika, Sydney, and I were part of Mom's Five Year Plan. Mom had wanted to spread out her children, having one every five years. This would ensure that she could give her children enough attention and be able to afford their college. Initially, she had wanted four, but two miscarriages after Sydney left her 5 Year Plan with only three. The last miscarriage transpired when she was four months pregnant. She was in the hospital, as a physician, delivering a baby, which she loved to do. She practiced at Sharp in Coronado, and found her job deeply satisfying. She had witnessed miracles, and was unafraid to be part of an older patient's end of life process. In opposition, she also loved babies. Although the debt she accrued to go to medical school was relentless, she was proud of her job. Before becoming a doctor she was an Occupational Therapist, who worked with special needs children at a local public school. While the woman was in labor, she fiercely kicked and swiped Mom's stomach, killing the baby inside of her. That was Mom's last delivery and last pregnancy, 3 years ago.

As the car pulled out, Sydney stood in the driveway with her closed mouth grin. When she smiled, her eyes pulled back into crescent moons. She held Roxy, the brown calico cat, in her arms. Danika, stick figure thin, rode her bike up the street as fast as she could next to my window, and waved lovingly. "I'll miss you," she yelled. The image of Danika with her white hair pulled back into a ponytail imprinted in my mind and I had a feeling, looking back that nothing would be the same.

After a month passed of my new college life, Parent's Weekend was here. Which was a good thing because I had become increasingly homesick. My family was close. Really close. We were one of the few families I knew that still ate nightly dinner at the dinner table, never missed each other's birthdays, and called each other regularly.

Once they arrived, I immersed them in my daily college life. We started off the day by dining on tacos and burgers in the DLG dining commons – the location described in Jack Johnson's song, "Bubbly Toes." That was kind of cool minus Dad's love/hate relationship with buffet style eateries. Since he grew-up the sixth out of eight kids, he often got to "chew on the bone," as he put it while the siblings ahead of him got the meat. But often times Dad would eat too much and pronounce, "I'm going to be sick! Why'd you guys let me do that?" he'd say jokingly. We also went to Alpha Delta Pi, the sorority I had joined. Yes, I had joined because of Mom, and because the school was overwhelmingly big and I did want to make it feel smaller. Each sorority had its stereotype (none of which were particularly nice). There were Coke Whores, Chubby Girls, The Blonde Sluts, The Rich Boring Girls. Alpha Delta Pi was The Party Girls. Of course I didn't find this out until I joined.

My family was in awe and proud of my sorority accomplishment – as not anyone could join. One must attend a week of "parties" called rush. Each day you were invited back to fewer houses. On the last night, if you were "lucky" you were invited into the "secret society." On my Preference Night, when most girls got two houses to choose from, I only got one. So it was like I had no choice. It was going to be the best thing to happen me, or possibly the worst.

Later, we arrived back at my dorm room, after we had spent the day on foot around campus and Isla Vista, where the Greek houses were.

The sun was setting over the Pacific, and I changed into a sweatshirt, exhausted and proud.

“So?” I started. “What do you think?”

“Really great Pokey, really—” Dad began.

Mom interrupted, “We are really proud honey. But your father and I also have something to tell you.”

Oh no, Sasha had died. A car must have hit her and they wanted to wait so I wasn’t overtaken by sadness and deep contemplation.

“It’s not Sasha, is it?” I asked.

“No, no, no.” Mom said, she grabbed Dad’s hand and smiled so that the creases next to her eyes wrinkled. “We are having a baby.”

I thought I misheard them. “*Who* is having a baby?”

“We are,” Mom said.

“How? I thought you were too old.” I took a deep breath. I was in college and wouldn’t be there for the baby’s life at all. I was too old to be an older sister again. This was much worse than Sasha.

“I thought so, too. It happened the night we dropped you off for school while staying in the Marriott. We had some champagne to celebrate sending our first baby off to college. And well, your Dad might have given me too much,” Mom said, elbowing Dad.

“We are shocked, too,” she added. Dad lightly laughed to ease the tension in the room. I just frowned out of confusion and discomfort.

“What if it’s a boy?” Dad asked. “It will be great, won’t it?” Dad reminded me of a smiley, happy-go-lucky character from the Brady Bunch which I admired about him.

“It will be really great Dad, really. But I think I’m going to go to sleep now,” I said as I started organizing my room, which I often did when I was done dealing with life.

“Are you happy?” Danika asked before she gave me a goodbye hug. Happiness was important to us. Mom loved to tell this story about when I was five. I had come up to her and asked, “Mommy, why is it so important to you and Daddy that I’m happy?” She thought it was terribly cute and strange – why a five year old would even think to ask.

Danika added, “Sydney gets to be a big sister.”

Sydney blushed and grinned, and removed her strawberry blond bangs from hanging in her eyes.

I hugged them, squeezing them close to me – as if my hug confirmed and showed everyone that I was on board. I was ready.

“Very happy, very very happy,” I told them.

III.

It may not have been my happy ending, but in my parents' minds, it would be the missing piece to their puzzle; to have a little boy spread joy through their home. My parents, Kim and Sam, were a special kind of people. They were both Midwesterners – she from Des Plaines, Illinois and he from Minneapolis, Minnesota – home to some of the coldest winters in our country. In their early twenties they both vowed to never shovel snow again and took a chance out west in the golden state, California. Now California back then was a growing state, as were its cities. They chose San Diego, as many transplants had, because it was still a small beach city and no one in their right mind could resist an even keel climate of 70s year round. They left the basements behind and signed up for patios and gardens in February. Back in the Midwest my dad had seen a tornado, a real life tornado. I'd only seen one in that movie, *Twister*. The only natural disaster they'd see out here would be a couple of earthquakes that mostly affected cities north of San Diego and El Nido in '92. Besides that, life, like the beaches, was easy.

And you know life can be a devilish, blessed, tricky bitch. The two of them met on a blind date! I've heard the story so many times, I almost feel like I was there. Mutual friends set them up. Dad had called her and asked her to meet him for a drink at the Harbor House in Seaport Village. She told him to look for pink shorts; she wouldn't be dressing up because my mother was not a woman to impress. He saw her, walking down the boardwalk with a bright smile, a loose ponytail with naturally highlighted blond hair, as if she had just finished her workout. They took a seat at the bar. She got a white wine spritzer, and he ordered a Heineken. She felt like she was on an interview. He asked if

she'd ever broken a bone (no), if she had a job (yes, she was an Occupational Therapist), et cetera. She thought, after this first drink that my father might be, you know, into hitting for the other team. He was a little goofy, had this boy like charm to him, and perfect hair, a spitting image of a real life Ken doll. She grew-up on the outskirts of Chicago but looked like a native Californian. She'd already gone through some trials of her own. For goodness sake, her first boyfriend, Jerry Jackson, sold weed out of her locker. At sixteen she had been the prime witness on a serial killer trial. Dad came from a private school background and his father was a lawyer, but he'd had his own trials, being one of 8 kids and losing his mom at eleven. Of course he asked her the hard questions, he wanted a woman who was healthy, sturdy, a woman who was special. He knew of life's fragility. One of their few and only differences was religion. They both believed in God, but my dad grew-up a Christian Scientist and my mother a Methodist – which they didn't think much about at the time because there was nothing to worry about. So they moved onto the next agenda of their evening: dinner.

After their drink she drove them, since he didn't have a car (he was living out here with his elder sister, Laurie, and they had their own private catering business) to “the best Mexican restaurant in town.” She thought maybe it would be one of those nice places, where the Mariachi band plays at your table, but when they pulled up she giggled. It was some hole in the wall place called Roberto's with a walk-up window to order. A couple buzzing flies lingered by the trashcans, and metal lunch tables that could probably use a good clean, resembled the dining area. He ordered two Carne Asada burritos for them, the best full-flavored grilled steak burritos you really couldn't get anywhere else,

especially not in the Midwest. This was real Mexican. The border was only a quick twenty-minute drive south. She agreed and told him it was the best Mexican food she'd ever had. He proposed six months later, and they were married within a year.

They had a marriage that made their friends jealous but also awestruck. People had called them the Rent a Couple, also Barbie and Ken, the fun, sporty, smart-witted couple you'd want at any and all of your parties! Don't get me wrong; they were by no means well off monetarily. They were broke most of their life, always in school loan debt. But they were rich in love. That soul mate kind of love you rarely see in a lifetime. It was a blessing/curse for their children. A blessing because they were an amazing example of what love was supposed to be and what it could be, and there in lies the curse. It was almost impossible to replicate, to come close to such a true, lasting, tested love.

Which was what it was all about – tested – to get the good things we created in life. It was not like we didn't deserve them, but we had to fight for the good, to experience the bad to really get that deep, satisfying prize like a fluffy, hot pancake felt warm in your belly.

Mom told me once, probably a few years ago when I was sixteen, "The best gift you can give your children is a good marriage." I prized her hard work and sacrifice. Most things Mom did made me weep with gratitude because everything she did – from cheering on the sidelines at a soccer game to going to the hospital to visit her sick patient – she did with enthusiasm, love, and care. I had friends that easily got mad at their parents. I tried to never because I knew our parents had good intentions, even when they

weren't perfect. It wasn't like they woke up one day and said, "Today I'm going to ruin my kids' lives." They were human.

They made mistakes.

At first I thought they'd made a mistake when Mom found out she was pregnant. There were inherent complications with a late pregnancy. Like disease or complications with the mother's health. Anxiety around a late pregnancy was normal. I was anxious because I had this feeling – kind of like a premonition but not that silly – that this was not right. The pregnancy. Like a bad omen you see in a nightmare. I had many nightmares during those nine months, more than I'd had in my life. Maybe it was because I was in a new environment, sleeping in an awkward dorm bed, or maybe I was right.

A friend once told me they thought I was born into a stressful environment because I seemed to be "on edge" quite frequently. Which was weird because Mom told me she put a lot of work into planning my birth. She wanted me to be born in the dark, which was supposed to be an easier transition from the womb to the world. The light would slowly be turned on, not so abruptly. I think I was anxious because I felt like the second Mom in the Lund family, being the eldest daughter. There were responsibilities.

Gavin is born on June 22, 2007. He is an easy delivery. He hurt his shoulder coming out but the doctor said it is nothing to worry about. The glow coming from my parents' faces is indescribable, it's as if they are children again, seeing something for the first time. Dad cuts the umbilical cord. He weeps while doing so, as he finally has his little boy.

Everyone is holding him. I am sitting in the corner, nervous.

To put off the event a little longer, I decided to open a window. The room had become claustrophobic with the nurses coming in and out taking vital signs, and now with the six of us here. A family of six, no longer five.

“Honey, do you want to hold him?” Mom asked sweetly.

“Me?” I asked. “Sure, of course.” I said, attempting to be enthusiastic.

“Here you go,” Dad said as he smiled and kissed my forehead. He handed me Gavin, with his mouth pulled up like a little kid. He was so proud to finally get his baby boy. How could I not be happy for him? And happy for Mom. This was what she’d wanted. *Wasn’t it?*

Gavin was light and small and cute. I touched his nose, ran my fingers down his arm, and counted his toes. All ten. Toes were something I paid attention to, as Mom only had 8, because cancer stole the other two. I moved his body wrapped in a blue blanket closer to mine. He looked exactly like Danika and Sydney had with golden blond locks, soft blue eyes, rosy cheeks, and smooth pale skin. I felt four sets of eyes watching me, waiting for a reaction.

“He’s great,” I said.

I looked down at him. My eyes were watering, and for a moment I felt safe. I took out my cell phone and took a picture of him and texted it to all of my friends, documenting his first day of life.

The first weeks of welcoming Gavin into the family had a warm, happy feeling to them. My nervousness faded after the first week he was home. I wanted to hold him all the time, rock him to sleep, and nuzzle my face close to his. I could hold him for hours and he loved sucking with his toothless gums on my bony knuckles.

“Ah, Gavin!” I’d cry when he clenched a little too hard.

I couldn’t wait for him to walk and talk. I’d be the best big sister, and take him to the park, teach him how to play hide and seek. Maybe people would think he was mine. I wouldn’t mind because soon enough I’d have my own babies and Gavin could mentor and play with them, too.

Then halfway through summer Gavin changed. At six weeks old, my little brother suddenly became alarmed about everything. One day the dogs – Sasha, Maddie, her daughter, and Brutus, the Chihuahua mix we rescued from Tijuana – howled at the distant sound of an ambulance. Gavin startled, his eyes crossed, and his arms flung in opposite directions. No one thought it was a big deal until he starting doing this all the time and for all noises – Dad blowing his nose, the slamming of a door, a sister laughing. He would have spells on Wednesdays of fevers over 101 degrees, with vomiting, and sharp, horse cries. He had been happy, and then he had become miserable. Fast.

“Mom, what’s wrong with him?” I asked curiously one summer day in between eating lunch and lying out by the pool.

“The doctors think he has a severe form of Meningitis that’s not going away,” she said with fighting eyes.

“What’s Meningitis again?” I had heard about it before.

“A bacterial infection usually surrounding the brain and spinal cord,” Mom said.

That sounded scary, but Mom said it was usually treatable.

I put a carrot into my mouth. “And what do you think?”

“I think it’s something else,” she gave me that all knowing motherly-doctor look.

I believed her. She was the doctor and the mother. But she wasn’t his doctor. She had to be his mother, and I think her not knowing exactly what was wrong with him killed her. She bounced him in her arms, wearing her tangerine, turquoise sarong wrapped over her bathing suit. He was paler than normal and looked weak. His bottom lip had started to droop and drool spilled out into Mom’s hair.

I walked away. I thought if I held him, I’d only make him worse. I stopped letting him suck on my knuckles. My hands could have been dirty, full of germs.

Around two months old he began having seizures. They would come unexpectedly, and usually after nights of little sleep. He barely ate. He shrieked with pain everyday, all day—and no one had a reason why.

The honeymoon came and left quickly. As best I could, I detached myself from the darkness growing over my family and returned to college in September for my second year.

IV.

The answer to my question on how to fix Gavin's new diagnosis did not come. It would not come for a week. So while I waited and tried to pretend this was all just one of those bad dreams, I partied. Probably too much. I was becoming someone my parents and sisters would frown upon. But my sisterhood convinced me otherwise. "It's what you're supposed to do. We are in college," one girl would say. "We are young and this is the time of our life!" another would say. Of course they told me to get up and go out drinking and dancing – they didn't have a dying brother at home, and they didn't know I had one either.

The weekend after the phone call had passed, and I had gone to every social event that I could. I sat in the chapter room upstairs watching reality TV, drinking coffee when I Kelly barged in. Kelly had been the one closest to me during this. She was with me moments before I received the phone call. Reflecting back, what a ridiculous way it was, to spend the last hour before normal life would end. We had been sitting downstairs in the sorority kitchen discussing Halloween costumes.

"Hey, Court. You got a letter!"

I thanked her and took the envelope from her hand. It was from my parents. I opened the envelope and could tell from the writing that the card started out with my mom's writing, and then turned to my dad's as the letter progressed.

Dearest Courtney,

We wanted to write you a letter because it was a difficult situation to call and tell you about Gavin.

We love you. You make us the proud parents we are today. Thank you for the thoughts and insights over the phone- we will handle this curveball and not at the expense of our incredible three daughters. Our lives will not always be surrounded by sadness. You and your sisters are our greatest joy and nothing will change that.

We are proud of you and the insightful person you have become. We want you to continue at school with your personal growth- watching you be happy and successful is great medicine for us during this stressful time.

We Love you the World.

Love, Mommy & Daddy

A tear dropped from my eye, and I quickly wiped it away. Nobody saw. I got up, walked out, and attempted to study for my Oceanography midterm.

*

Three days later, when I walked into my Oceanography lab, Alice, the teaching assistant passed out everyone's generic green scantrons, with a bright red number circled on the top revealing a grade from the midterm. She set mine face down on my desk. When I turned it over, I was in shock. My grade from the midterm: 37 percent.

I felt like I had the wind knocked out of me. Now not only was I failing at coming up with a plan, I was failing at the only thing I knew how to do right.

I waited until everyone left the lab at the end of class to take the time to speak with Alice, to try and salvage my grade. I approached her and felt my stomach churning, my eyes burning, as I fought back the tears.

“Hey Alice—” I said.

“What’s going on, do you have a question?”

I fumbled with the scantron in my hands.

“This grade, is—the worst grade I’ve ever received,” I said. “I’ll fail out of the class with this grade.”

“Well, you could’ve asked questions before the midterm,” she said.

“I didn’t even know what to ask,” I said.

Standing in front of her I felt helpless. Unfortunately, Oceanography was my least favorite class, and I had never even talked to Alice except when she asked me if I had any questions. I always replied “no” because denial was easier.

“I’m sorry,” I balled. “I have this brother...who I think is dying...I couldn’t take my mind off that to study for a midterm I know nothing about.”

My mind was somewhere else, somewhere I had been running away from for quite a while. I gave her the run down about Gavin, and the despondency that came with his sickness, that I pushed down, deep inside of me. I thought she was going to look at me like I was crazy, a mess of tears and emotions. Instead, she gave me a hug.

“You look like you need a smoothie,” she said.

I laughed. A smoothie? That sounded nice. Then, she too, confided in me that she had experienced a similar situation. Finally, she gave me hope. Alice suggested the idea of taking a medical leave.

“It’s normal. Things happen to people and families that are out of anyone’s control. The best advice I can give is to go be with the people who need you most. You can make up the missed quarter in summer school,” Alice said.

At that instant I knew. I knew exactly what I needed to do.

I ran from the science building and slammed down onto the closest patch of green grass I could find. I sprawled out on it, with my face staring up at the foggy, grey Santa Barbara sky. I picked up my phone, took a deep, long breath and called Mom. I sat there screaming, crying as I talked with her.

“I’m sorry,” I said. “I can’t do this. I can’t try and be normal at school while this is happening at home! It’s too hard.”

I knew my parents wanted me to stay and do well at school, but I couldn’t do it anymore. She gave me a simple reply.

“I am proud of you for lasting this long,” she said.

After the phone call I stood up and walked home. Back at the sorority house, I wondered how I’d break the news. I had only told my closest friends about Gavin: Laura and Kelly. Luckily when I entered Kelly’s room, the two of them were hanging out alone.

“Hey guys,” I said, as I entered the room.

“Court, what’s wrong?” asked Kelly

I was such a mess, more snotty tears rolled down my face. I wondered if I was ever going to be able to keep it together. I was embarrassed to tell them I was withdrawing from college. And maybe never coming back.

“It will be good for you to be with your family,” Laura said.

“Court, we love you!” Kelly said as she jumped to wrap her arms around me, and Laura joined.

Dad came around noon the next day. I was packing the last of my bags when I saw him in the doorway of my room. I jumped when I heard my name.

“Daddy, you know there’s no boys upstairs.” I said and gave him a hug. We both pretended like nothing was wrong.

“Where’s everyone?” he asked.

“I don’t know, out doing something,” I said.

He was excited to say hi to my friends, but the house was empty. The girls were day drinking with the fraternities.

“Let’s get going. I’m ready to get out of here,” I said.

We packed my stuff tight in the trunk of the Suburban, and it was time to go home.

For half of the car ride home my dad listened to a book on tape, “The Kite Runner.” It was on my list of books to read. I sat in the passenger seat and remained quiet as I listened to music on my iPod while secretly listening to the audio book. Miserably, I found solace when a character said, “Sad stories make the best books.” It taunted me,

because even though I hated to admit it, I was living a real-life tragedy, a type of sad story I had only experienced in books, never as a living, breathing phenomenon. And that I was going to write through it, to document it.

After two hours of silence from my father, I couldn't take it anymore. Dad came up alone so we could talk, not so he could listen to a book on tape the whole four hours home. I ripped my headphones from my ears and murmured with an angry undertone, "You and Mommy both always say you want to talk, but never do."

"We've been waiting for you," he replied.

"Well, I don't know what to say. I've been avoiding you guys because I'm scared, I'm scared about not knowing, not knowing what is going to happen with us, with Gavin, with our family."

"I know, Pokey, I'm scared too," he said.

Pokey was a nickname from when I was an infant. Him and Mom said I had chunky thighs that were fun to poke at so the name stuck, but Dad was the only one in the family who still called me Pokey. This was the first time I saw Dad as a real human being, with real emotion—emotion beyond the façade of cheer even I had successfully learned to portray. He was good at pretending nothing was wrong. He related our situation to his childhood memories of his mother's death.

"When my mom died, I didn't know she was sick until the day she died. No one told me," he said. "It tore my family apart. And—I'm afraid about the same thing happening to our family."

“Don’t worry, Daddy, we are too strong of a family, we won’t let that happen, we can’t,” I said, as I tried to play parent. But inside, I was scared, too.

“If my only boy dies, I don’t know if I can go on,” he spoke softly, holding back his tears.

My heart broke. I looked over to him from the passenger seat, and saw his lips begin to quiver. I gently placed my hand on his that was guiding the stick shift, and he burst into tears. I had never seen him this vulnerable.

“We’re living a real life horror film,” he said. “And we’re all the stars.”

I took a moment to think of the horrific metaphor of our life.

“No,” I said. “We’re too strong, we can make it through this. Things will get better.”

“Yeah, well, prove it,” he said.

I couldn’t prove it. But I thought of the best example I could.

I remembered a singular morning a few weeks after Gavin was born. It was of my step grandmother, Barbara, chopping onions for egg salad, which she always did when she and Grandpa Buddy, Mom’s father, visited from Illinois. The way she chopped it was uneven, sloppy, her long red acrylic nails getting in the way. The way she hacked the onion was the way I viewed her. Which was to say, perhaps, the way *I thought* my parents viewed her: a “step” person, who was an ex-smoker, with a past of ex-husbands. From a young age I had dehumanized her. I did this for a lot of things and a lot of people – my parents’ views were my views. But something about this moment, her relentless dedication to fit in with the family broke me. I sat down next to her and asked her who

her ex-husbands were, I asked her to tell me her story. She said she had an abusive husband at eighteen, her next husband had a mental illness and walked in front of a semi truck on an icy freeway in the middle of the night, and then, her final husband would be my grandfather. I understood, perhaps, why Dad and Mom portrayed both their stepmothers in a certain, unlikeable way, because they could never replace their real mothers, their deceased mothers. Not for a second. But this didn't mean I couldn't form an opinion on my own, which I would soon be doing quite freely.

Dad was blowing his nose on his sleeve when I was done assembling my words.

“Grandma Barbara once told me about her ex-husband who committed suicide. After the horribly hard times she met grandpa Buddy, her soul mate, the man of her dreams,” I said. “She advised me, ‘Courtney, with a tragic event like this comes something good. Something greater that you have ever had before.’”

“I can only hope you are right, Pokey.”

I was worried. If my own father could barely keep his sanity, and hold himself together, my mother would be worse.

When we first got home, I noticed things were different. Mom's garden in the backyard was dying. The sunflowers were tinted brown and drooping. And so was everything else—the peppers, tomatoes, zucchinis and squashes were all dying. When I stepped into the front living room, I noticed strange named medicines strewn across the counter-tops. Sympathy cards were equally as present. The fridge was full of pre-made casseroles and day old meatloaves dropped off by friends, neighbors, and strangers. People knew.

When I saw my mother for the first time, her eyes were sunken in, as if she'd been crying for days. Wrapped in her arms was Gavin.

"Hi Mommy," I said.

"Hi Sweetie," she said, and pulled me in for a tight-gripped hug, squishing Gavin between us.

"Do you want to hold him?" she asked, after she stepped back from our hug.

I was scared to hold him, yet he was beautiful, bundled in the warm, woolen blanket.

"No, it's okay. Maybe tomorrow," I said.

I carried my bags upstairs and plopped down on my old bed. I looked around the room at the happy pictures of my high school friends and me, the swim and water polo trophies, and an old framed family photo. This was no longer the home I had spent my adolescent years learning to love. The energy of the house felt different, like I didn't belong, like no one belonged.

Part Two: Home

I.

The next morning I slid into the bathroom, exhausted. My blonde hair was frizzy, face breaking out, and the crease between my eyebrows was extra deep. My movements were twitchy, jerky. I'd let this whole Gavin thing get to me. I called his diagnosis a "thing" because I couldn't bring myself to believe my brother was dying. I was scared to go downstairs and face Mom and Gavin. That would make Gavin's disease real, and I wasn't ready for that.

Home was quiet and cold. I tiptoed downstairs and noticed Gavin sleeping on the couch while Mom typed on the computer nearby. "Good morning honey," she said when she saw me, and gave me a hug and kiss on the cheek. "I'm so happy you are here."

"Me too," I said, unsure about how I really felt waking up in my high school bedroom instead of the sorority house. "How's Gavin?"

"He was in pain all night, woke me up every half hour. Motrin didn't work so I gave him his Morphine," she said. Morphine was the only medicine that soothed his pain. The morphine, Mom said, was a source of relief when the calcifications formed, causing his permanent brain damage. "If he were an animal we'd put him down by now," she said as she picked up one of her used tissues and wiped her eyes.

I couldn't tell if she was serious about that. Her comment reminded me of Sierra, our white horse who got put to sleep in our backyard when I was fourteen. Mom told me not to watch because I'd be traumatized if I did. I watched anyway and the image of her limp body and lifeless hooves sliding across the wet grass still haunted me. I looked over

at Gavin. He wasn't an animal, but Mom was right. If an animal were sick and dying for four months, we'd put it down.

Gavin didn't look like he was dying. I thought he was very much a Lund: thick blonde hair, blue eyes, translucent body hair, and unfortunately pale skin. If he didn't have the disease he'd probably enjoy inappropriate jokes, become a Junior Olympic swimmer, and like eating the crispy folded potato chips that Dad did. Dad had wanted to share these and more with Gavin. He always talked to us about how lucky we were to be a Lund. He called us the Lucky Lunds. We were athletic, smart, happy, fun, healthy people. But Gavin wasn't any of these.

"What are you doing on the computer?" I asked. I never saw Mom spend free time on the computer.

"E-mailing another mom of a child with AGS," she said. "Her name is Nicole. I'm asking her if we can talk. Sometime soon, I hope."

That made sense. Since the disease was so rare, her largest source of information came from other families with children who had Aicardi-Goutieres Syndrome. Few American doctors knew anything about it. The only doctor in the world running tests on the disease was in London.

I let her continue typing. I didn't want to disturb her because I knew that when Gavin woke, she might not get a chance to sit down at the computer for the rest of the day. I went to the kitchen and opened the refrigerator to look for something to eat. Our cabinets and fridge were always stocked with good snacks and delicious home-cooked meals Mom had made, my favorite being her pasta. There was more food than I expected,

and in containers that were not Mom's. There were ready-made casserole dishes with heating directions written on post-it notes. I opened the freezer and there were more: lasagnas, enchiladas, tamales, and turkey dinners.

“What’s all this food for?” I asked.

“For us,” she said.

The Girl Scout troop Mom led had developed a daily schedule of dropping off prepared meals to be refrigerated or frozen. There were also meals from neighbors and friends with “praying for you” notes attached on them.

“Help yourself, honey.”

“No, thanks.” The dishes and notes meant that people knew about Gavin’s unlucky life, and knew I was the oldest sister of a severely handicapped brother who was dying. It was no longer a secret between us. I didn’t want to eat anyone’s sympathy food.

Instead, I made a hot cup of tea and paced for a little before I sulked my way over to the kitchen table. I massaged my temples and stared down into the orange tablecloth decorated with images of fall leaves and pinecones, twirling around the table in delight. This was going to be a hard fall, and an even harder winter.

Mom joined me at the kitchen table to finish her coffee; I think she noticed my uneasy pacing. I looked out the window into the rose garden covered with grey ash. Dad and I used to love growing red roses and entering them in local fairs for contests. One year Dad submitted mine in the adult category when I was seven, and I won a blue ribbon for best looking rose. I missed those days, the easy days. The roses outside looked

stripped of life. I doubted anyone watered them or tended to their soil. The ash from the San Diego fires made them look worse.

“The car’s packed in case the fires get close,” Mom said.

“They won’t get us,” I said. “The ash just makes it look like they will.”

“I hope not, I’d have to let the horses loose on their own,” she said.

I pictured the fire moving through the acre of our backyard: snipping at horse’s tails, bunnies bouncing aimlessly through dark soot, and chickens screeching from their coop with fear. I imagined myself caught in the midst of the fire trying to guide the animals to safety; I couldn’t watch them die. When the fire would get too strong, I’d realize I couldn’t save them after all. To try and save myself I’d jump in the pool, and hold my breath underwater.

“Yeah, I hope not,” I said.

She grabbed two cards from the counter and placed them in front of me when Gavin started to cry. “Read these while I get your brother. Thirty minutes; that’s the longest he’s napped,” she said.

Mom picked Gavin up and held him close. “Today’s not going to be a good day,” she said from the living room. “The Monster is here.”

The Monster was a name Mom made up. She used it to describe AGS and Gavin at its/his worst. Monster days consumed Gavin: high fevers, seizures, throwing up, and loss of color in his skin tone. It came often on days when he had little sleep the night before.

Gavin's cries pushed me further away from him. He looked as if he were a monster: his face was red and blotchy; his lips were purple as they quivered; his eyes went out of focus; and his limbs clenched tight as if circulation stopped flowing through them. Sometimes his left leg would shake until Mom held it long enough to stop. When the Monster hit, the calcifications being formed in his brain stem were excruciating. He'd lose protection around the nerves, creating agonizing nerve pain. It was like someone struck him with a Cattle Prod.

Mom didn't understand why I didn't want to hold him, but why would I? I couldn't help him. I picked up the two cards that sat on the table in front of me. The first card, addressed to Dad, read:

MYSTERY

"The Journey of life is so beautiful that it needs no destination."

October 29, 2007

Dear Sam,

Your news today has the staff reeling. We all grieve with you, Sam. When a journey has a paradigm shift like this, it must seem impossible to get your footing again. Fathers have so much put on them. You must feel so forlorn and helpless, but this mystery will be enshrouded. Great gifts come with great adversity. I'm so sorry your family has this sadness. Divergent grieving trolls around creating havoc and confusion so that nothing seems like it will ever be the same, or same again. Through it all you will teach your girls a lot. Gavin is such a beautiful baby- a miracle, and a mystery. I will pray for all of you.

Love, Kate

Second card, addressed to my mother, read:

Find Strength.

Kim, My Dearest Friend,

When life put its challenges before me, it felt comforting to know that those who mattered most to me truly understood the journey that I was faced with. I believe that's when God gave me YOU. As I did some research on Aicardi-Goutierres Syndrome, I've come to realize just what a challenge you, Sam, and the girls are facing. God blessed you with Gavin because you are who you are. It was your love that carried me through the days that I thought no one cared. You are not only a blessing in my life, but one that I've gained my strength from. Now God has blessed you with a special little soul to share your love and strength with; someone that will NEVER know what it's like to be without it. God is TRULY good!

Please know that my heart is with you through every moment of everyday. The miles between us may prevent me from holding you through the tears, but certainly does not damper my love, thoughts, and prayers for you. I am ready to walk this journey with you- all you have to do is call and I'll be there!

Give Gavin a kiss from me, rub his cheek, and tell him how much I love him. I miss your love, smile, but most of all- your touch!

I love you baby, Crystal – Feel Peace

I set the cards back down; they were supposed to implement those fog-like feelings that cloud the deep pain and uncertainty. For the first time, I wondered about God's role in this. People loved to say how great God was, but how could I know? What kind of a God took the lives of innocent babies? Gavin was just over four months old, according to the "plan" he had about eight months to go. I shuddered at the thought and I looked over to the living room. Mom bounced him up and down on a yoga ball. He cried with fiery cheeks and parched eyes, but with each bounce, his cried waned. There was something about the motion that calmed him momentarily. I looked at Mom's eyes. They were wet and bloodshot. I wanted to hug her, and cry with her; she looked lonely and over-worked. The home phone rested by her feet. She carried it around with her, hoping someone would call with an answer.

The next day, after Danika, Sydney, and Dad went to school and work, I was left alone with Mom again. She looked worse than the day before and a little angry. She was still in the same red turtleneck, and her hair looked like it hadn't been washed. I asked her how she was.

"I take it day by day," she said.

“Day by day?” I couldn’t grasp the meaning. All I wanted to do was fast forward through this. Day by day sounded so depressing. My mom was not depressing. Who had taken my cheery mom and replaced her with this?

“It’s so hard and I feel like I’m doing it alone,” she said.

“What do you mean? I’m here,” I said. I wasn’t helping; she was doing it alone. There were dishes piled in the sink from last night, and laundry, clean and dirty, piled everywhere. “I can clean.” I felt like a self-centered jerk for not doing it before as I began picking up laundry and folding it.

“No, it’s not about that,” Mom said. “It’s your dad.” Now that I thought about it, I hadn’t seen much of him over the past forty-eight hours.

“He is totally disengaged with Gavin,” she said. “And me.” I was not the only one who was avoiding it all. I wondered about the last time they’d done it. When they had sex, the next day Mom would wear one of Dad’s Hawaiian shirts with a big smile. It looked silly, but she was happy to wear it and have his scent on hers. They’d kiss and grab each other’s butts in passing. She didn’t know, but I knew. I hadn’t seen any Hawaiian shirts, butt grabbing, or kissing in some time.

“He’s just busy with work,” I said when there was a knock on the door.

“Can you get that?” Mom asked. I opened the door to a short, unfamiliar woman in her mid-fifties with a calm demeanor and soothing voice.

“Hi, I’m Judy from Hospice. You must be Courtney,” she said.

“Yes, it’s a pleasure to meet you,” I shook her hand and acted overjoyed to meet her, but I despised her. Judy was the enemy. She was worse than the frozen dinners

because she was real; she represented the end. Judy, Mom, Gavin and I sat in the other living room, the one we never used. I fidgeted in the couch across from her, and played with my hands while she spoke to me.

“Let me tell you a little bit about what we do,” she said. “The role of a hospice worker is to comfort and ease the patient and family through the process of dying. It is an alternative to the patient dying in the hospital or another facility. It allows them to pass from this life in the comfort and familiar surroundings of their home.”

All of a sudden I felt very protective over Gavin like I was a mother bird, and gravity was trying to steal my baby from the nest, pulling him down to the ground as he dangled in limbo between life and death. I grabbed Gavin’s hand and kissed it. It felt pudgy, smooth, and warm.

I nodded, and didn’t say a word as Judy finished up.

“Do you have any questions?” Judy asked. “No,” I said.

Judy and mom went on chatting, and I had by now caused my thumb to bleed. Judy stopped mid conversation when she noticed the bleeding.

“Are you alright?” Judy asked.

“I’m fine,” I said as I ran to the kitchen to grab a Band-Aid. From the other room Mom yelled, “You got to stop that picking habit. You’ll get an infection.”

Gavin was weighed and measured. He weighed in at a low sixteen pounds; he’d lost a pound since last time she weighed him. I wondered if that made Judy happy because the sooner he died, the sooner she’d be done with our family. Mom looked relieved to have Judy here. She later told me the hospice service was free, and that if he

was going to die, it was nice to have professionals help us through it. But in my heart, I knew he wasn't going to die. He couldn't. By blood he *was* a Lucky Lund.

When Judy left, I urged Mom to leave the house suggesting it would be good for her, or for me. I didn't know the right way to act, but I knew staying in the house wasn't necessarily helping. She had a gift card to Babies 'R Us and wanted to spend it.

We packed up the car and put Gavin in his car seat between us. He smelt of spoiled milk, and didn't seem to like the car much. We took turns shushing him and holding the binky in his mouth. When I held it tight against his lips he'd push it out with his tongue, and go back to crying. The binky was our earplug. After five minutes I gave up and let the binky sit in his lap as he cried. Mom picked it up and held it in his mouth with one hand and steered the wheel with the other.

"Is he always going to cry like this?" I asked, annoyed at my lack of patience. I admired Mom for hers.

"I talked to Nicole today and she said the irritability gets better after the first year," she said. So it was a battle of the first year of life with this disease, I thought. During the car ride she told me about her conversation with Nicole, from Vale, Colorado. Nicole was the mother of three children. Her three children: Emma (5), Thomas (3 ½), and Tucker (2 ½) were, like my mother's, her pride and joy. Tucker, her last also like Mom's, was affected with AGS. During their talk Nicole told Mom her secrets to making life with AGS work. What stood out the most to Mom was Nicole's relationship with her husband.

“Nicole told me she and her husband separated for two months over the period the diagnosis was revealed,” Mom said. “But she also said that they are back together now and going on lots of dates.”

Nicole told Mom that when Tucker was around a year old she would have a babysitter from 10 pm to 6 am on Sunday nights, giving her and her husband a decent night sleep. AGS babies only slept five hours a night.

“What else did she say about Tucker?” I asked.

“Tucker is blind, doesn’t smile, and expresses few emotions with his mouth, so Gavin is a little higher functioning. They have taken him on vacations, which is a dream of mine, to take your brother on a plane. She believes in alternative therapy like acupuncture,” she said. “But the best thing was that she reminded me, even though it all seems hard, you continue to live, and have to remember all that you are blessed with already.”

I was happy Mom was making friends with women across the country and across the world. She said she’d gotten in contact with a mom in Canada and another in Brazil who she liked.

As we walked through Babies ‘R Us Mom grew oddly quiet. We were walking down the baby boy aisle when a dolled-up woman pushing a cart with a baby stopped and stared at us. She looked at Gavin, and made a face that read: *What’s wrong with you?*

Mom noticed and said, “He was about Gavin’s age. If Gavin was normal, he’d be sitting up like that baby, too.”

It was the first time I'd seen an outsider's reaction besides Judy who didn't count. Gavin *was* different: he held his hands close to his chest like a dinosaur, was abnormally skinny, and always lying down. He couldn't sit up, use his hands, legs, or kick his feet like the other baby had. I felt like a knife was jabbed into me, into us: Mom and me.

She ignored commenting on the woman's stare. She picked out a baby boy's outfit with a baseball and glove sewn on the front and held it up. Mom made a sad pouty lip, and tears started coming down her face.

"I'm so sorry Gavin," she squeezed him tight. "You'll never get to play baseball and run and play like the other boys." He looked into her eyes and smiled. She kissed him all over.

I wanted to join her, and kiss him all over, too, but I couldn't. The feeling was like trying to scream in a dream, and nothing comes out; my body felt paralyzed.

When we returned home, I thought of Mom's fear of losing Dad. At least three times today she brought up percentages of failed marriages due to a handicapped child. It started off as 50 percent, and by the end of the day she turned it into 85 percent. This scared me. When Dad got home from work, I went to talk to him in the garage.

He had a beer in his hand and was watching sports on one of his five TVs. He had turned fifty earlier this year, but still had a head of hair like a twenty year old. He described his hair as "pre-ceding," as opposed to receding. Over the years it just got thicker. I loved my dad, but seeing him act carefree, as if nothing was wrong bothered me.

I opened the garage fridge to grab a Diet Coke for Mom.

“You have to man up and ask Mom on a date,” I said. He laughed and said,
“We’ve been married for twenty years. Married couples don’t do that.”

“It would be good for both of you,” I said. “ She needs it.”

He replied, “She can ask me.”

I felt my body get hot inside. Was he not hearing what I was saying?

“Well she isn’t going to ask you anytime soon, so you better toughen up and do it,” I said as I walked out of the garage and slammed the door. I hoped he would for the sake of our family and their marriage. If we were the one in a billion to have this disease, we could not lose the matrimony battle.

II.

My parents weren't the Rent a Couple anymore. You didn't want them at your party because they couldn't bear look at each other. Mom was melancholic. Dad had a fixed preoccupied look on his face. We stopped eating dinner at the table, and we were rarely all home at one time. For most of the days I'd been home it seemed as if Mom, Gavin, the Hospice and/or social workers, and I were the main inhabitants of this house. I didn't call it a home because it felt more like a medical ward in a prison. I couldn't think of a worse punishment than to drag a family's youngest boy through a year's worth of pain, and then take him. What was the point? Even though I was Protestant I had Catholic guilt. I often thought of the things I did to deserve this. If I wanted to be extreme, of course I could find those bad things I did like steal make-up from Rite Aid in high school. But that wouldn't accomplish much; I could not undo what was to be done. I had eleven months to learn to love Gavin.

I tried to cheer Mom up during our days at home, but what she needed was a healed Gavin, and nothing I could learn within the year could bring her that. The person she needed most, Dad, spent his time in the house hiding in the garage and at work as a high school Vice Principal. Danika stayed active in high school soccer. Sydney hung out in her bedroom, reading endless vampire novels. I started going to the gym and working at a restaurant downtown. We all had our something, all except Mom. She had no escape.

I arrived home from the gym and saw Mom and Dad staring at each other from opposite couches, speechless. All I could hear was Mom's pasta sauce popping and

bubbling on the stove, filling the room with an aroma of oregano, garlic, and tomatoes. It was comforting for the moment.

“Am I interrupting something?” I asked.

Mom wouldn't look at me. I recognized her familiar bloodshot eyes. Gavin lay in her lap asleep.

Dad greeted me, “Hi girl. Back so soon?” Mom remained silent.

“What's wrong?” I asked.

“I'm leaving tomorrow,” she said.

“What are you talking about?” Her face was red and puffy. She sat upright, zombie-like. Her body seemed to no longer belong to her.

“My life sucks and I need to get away,” she said. “I'm leaving for Kathleen's house in the morning.”

It was over a ten hour drive up the coast to San Francisco where Kathleen, her college best friend, lived. The drive would be impossible. Gavin didn't travel well in cars. There was no way the two of them could make it on their own.

“You can't do that,” I said. I looked at Dad for some help. He stood up and snatched his keys and wallet from the counter.

“I've got to take Danika to soccer tryouts,” he said.

“Really? Right now?” I asked.

“Yep,” he said. He shut the door and was gone.

The three of us were left to the silence once again. The smell of burning pasta swam up the canals of my nostrils. I looked out the window into the backyard sky and felt gloomy, isolated. I shuddered, and glanced back to Mom.

Two days earlier I had decided to become vegan. I mused the limits and rules of living a vegan lifestyle. It would give me purpose and structure, something I craved. While I was busy unpacking my new vegan groceries from Trader Joe's, I saw Mom hunched over the white countertop. She looked sad, staring down at a bright yellow notebook with a dark contrasting sticker in the top right corner. The sticker read: DNR.

"Mom I'm turning vegan. I'm sick of all this food here," I said. She didn't respond. She kept staring at the yellow notebook while I put away sprouted bread, soy yogurt, carrots, hummus, tofurkey, and organic peanut butter sandwiches.

"What are you doing?" I asked as I paused to snack on a cracker.

"DNR. You know what that means?" she asked.

"No. I don't think so."

"Do Not Resuscitate."

I put the tofurkey down.

"I signed Gavin's rights away today," she said. "If he's choking or seizing and not breathing anymore, this sticker tells paramedics not to save him."

I put my white hand on her freckled tan one. She squeezed mine then let go.

"I want this to end," she said. "It's not fair to him. Or to me." I wiped a tear falling down her cheek and she broke down in tears.

“But—It’s okay.”

“No. I’ve been thinking lately. One of these days I’m going to drive off the Coronado Bridge with Gavin. That would be an easy death,” she said. “Or I’ll drive us to the middle of the desert for a slower one. We could await the end together.”

I backed away from the counter that divided us. The space we shared felt like it was shrinking, the white walls caving in on me. She looked over to him sleeping on the couch, “Anything would be easier than this,” she had said.

We heard Dad’s car start and his and Danika’s car doors close. I sat on the purple couch Dad left minutes before. I grabbed a wildly patterned couch pillow and put it over my stomach. The pillow had lines going every which way like an abstract Picasso. Various purple hues were crisscrossed with black and gold ones. I felt a hole at the top, most likely chewed open by one of the beagles, spilling out the inner contents. I brushed a warm tear away. I couldn’t let her see me cry.

“You’re the mom. You have to stay.” I thought about if she were never to return.

“I can’t do it alone anymore, honey,” she said. “Your father’s not engaged emotionally or physically with Gavin or me.”

“But what about me?” I asked. “I’m here.” I fumbled with my pink lanyard. It was printed with my college letters. It held the keys to my life in Santa Barbara.

“Gavin’s not your child, he’s his,” she said glancing down at a sleeping Gavin.

I couldn’t let Mom leave me; leave us. Sydney was ten. Danika was barely fifteen. I still had my life to live. What was she thinking? I hadn’t even had a real

boyfriend or graduated college. I couldn't be stuck as a stay at home sister-mom in the bubble of Bonita. I wanted to explore the world and leave my mark. What if Dad left, too? I imagined us as orphans. Three girls in a ransacked apartment in the ghetto of Chula Vista with neighbors slinging drugs, and rooms decorated with rat feces and dead cockroaches, our acquaintances ex-felons and escaped murderers. We'd eat second hand expired cans of Spaghetti's, stale bagels, and oranges we stole from public parks, rinds included. It was an oddly satisfying, child-like image. I pulled myself out of it.

"Come on Mom! I'm trying to help. What do you need Dad to do? What do you need me to do to get you to stay?" I realized I didn't trust her.

She must have sensed my desperation, my fear because she paused to think about my question before she answered.

"Well. To start he needs to learn how to give Gavin a bottle."

"Fine." I had a fleeting feeling of hope.

I ran upstairs to take care of some things. I hated being the messenger, but someone had to do it. First I texted Dad, "Offer to take time off from work. Help Gavin learn how to take a bottle. It's the first step--and a greatly needed one."

Secondly, I called Mom's only sister, Aunt Karylee. I told her what I knew about Mom's suicidal thoughts. Frightened, she called a counselor to come to our house at 3 PM for a family meeting.

While I waited for the counselor I sat in my bedroom rehearsing how to tell the truth about Mom. Would I blurt it out in the beginning? Would I wait to the end and tell

her in private? As the oldest sister I felt it was my duty to save Mom and the family. I couldn't control Gavin's disease, but I thought I could control my family, somehow.

Deborah, the social worker, arrived on time. She looked over-caffeinated with jittery, anxious eyes and smelt of cheap Vanilla perfume. She sat with the six of us in the living room we never used; not the one with Picasso pillows, but the one on the other side of the stairwell decorated with a Native American touch, now being used quite often. Since being home this was the first time I saw my family together in the same room. It felt nice.

"How are you all doing?" she asked.

I looked around. We looked cheery. What kind of people looked cheery when there was a baby in the room who was dying? All of us except Mom could fake that everything was fine. Danika and Sydney sat there, smiling politely back at her. Dad cracked a joke and smiled instead of answering the question. Gavin hung to Mom like a leech, sucking away at everything she had. I stared at her, wondering how this would work.

"We're not doing well," I said. I wasn't going to let Dad talk first and say everything was fine because it wasn't. Deborah, Judy, the meals, and the gifts people dropped off daily were a constant reminder that nothing was okay. Mom's eyes were my strongest reminder.

"You may not be able to see it, but we're kind of suffering here," I said.

We spent the next twenty minutes talking about how Gavin's disease had affected us individually. Sydney started with her story.

“I don’t really know what’s going on, but I’m sad. I cry a lot and it makes me more sad when I see others cry,” she said through tears.

Since she was the youngest she often got lost in the shuffle. She was still a baby and Mom had not given her the attention a pre-adolescent girl needed.

When it was Danika’s turn to talk, she cried, too.

“I don’t know what’s wrong with Gavin, but I cry all the time,” she said.

Her cry sounded like the cry I used to have as a child when I fell and scraped my knee. It was a delayed cry; as if shocked she was crying at all. She choked for air between her words and tears. Danika didn’t cry often. She bottled up her emotions like Dad. She wasn’t like Sydney, Mom, and I who poured out emotions without filters. I put my hand over my mouth because for some reason listening to Danika made me giggle. She cried like a hyena laughed.

Mom and Dad’s eyes glazed over. They hadn’t seen us kids cry over this yet. Mom lived in her and Gavin’s world. Dad lived in his. When it was my turn to talk I felt hot inside. I scratched at my hangnails and bit the inside of my lip.

“And how is this affecting you?” Deborah asked me.

I took a deep breath. “I’m scared.”

“It’s normal to be scared with a rare disease like—”

“No,” I interrupted. “I’m scared because my Mom has thoughts of ending her and Gavin’s lives.”

Everyone’s attention moved to me. The room went silent. Mom began shuffling awkward in her seat and Deborah pushed her glasses closer to her eyes.

“Girls, time for you to watch TV in the other room,” Mom said. Dad waved them out of the there.

When Danika and Sydney left Mom frowned at me while Dad stared at me with an expression that seemed to say: *Are you kidding me?* I felt like Macaulay Culkin in Home Alone, the “little jerk,” always pissing the adults off without knowing he was doing it.

I told Deborah what Mom had said. Deborah seemed untrustworthy by the way she scribbled down notes quickly in her notebook. She held the cap of the pen in her mouth, not to miss a word. She asked me the truth and I told her. I told her about the bridge. I told her about the desert.

Mom sat frowning at me. Dad couldn’t believe it.

“Kim, is this true?” Deborah asked.

“Have I thought about it? Yes. Would I ever? Absolutely not.”

By the end of the meeting Mom seemed to have convinced Deborah that she had no intention of hurting herself, and that going to Kathleen’s would be this sort of necessary vacation from Dad and home. I still hoped she wouldn’t. She had lost my trust.

After I was done talking, and the attention shifted from Mom’s suicide-talk to the tension between her and Dad, I ran upstairs to get ready for work. I put on my black work pants, black tank top with a big red lobster in the front. I painted on heavy black eyeliner. With enough eyeliner, I was invisible.

On my way out I stopped in the living room. “Bye, love you,” I said as I kissed Mom and Dad on the cheek. “Don’t do it,” I said to Mom.

I was a hostess at Rockin' Baja Lobster, a Mexican restaurant downtown. It was a decent job and I was thankful for work. At the restaurant I had to act like I was happy. I used my Mac make-up to paste a bronze, healthy glow to my pale skin and straightened my hair. Fake tanner became sort of like my savior. It transformed me from the pale melancholic thing I had become. I thought all this acting-to-be-happy would be good training for when the time came to be happy again. I walked up to the host stand where Abby, a bubbly friend of mine from high school, was already standing.

"Hi Dog!" she said.

"Hi Bear," I said. We gave each other a hug. Abby was always a pleasure to see. She liked to call people animals, specifically "dogs" and "kitties." She referred to herself as "Bear," so I did, too.

"Your fur is getting long," she ran her fingers through my hair.

"I need a haircut. Want to get one tomorrow?" I asked.

"Yeah!" she said. "You ready to work?" We laughed.

I enjoyed working with Abby because she brought out the mischievous child in me. "I think so," I said. "What are we going to do tonight?" I asked.

We had become good at entertaining ourselves during the slow nights of winter. Downtown San Diego was busiest during baseball season in the summer. Petco Park was recently built and only two blocks away. The park was a magnet, drawing crowds of booze and food hungry people to the restaurant. On baseball nights the restaurant roared with excited fans and sports television. We'd be on a wait of forty-five minute wait for a table, and running around sweating, pleasing customers with hopes of their return. But

when the first inning rolled around we'd be empty. The customers were off to the main attraction. The San Diego convention center had a similar effect. It was three blocks away, which provided a full restaurant during lunchtime. The winter nights were dead. They were ours.

The bright fluorescent lights of the Hard Rock Hotel being built across the street clouded my mind like a Hollywood dream. When guests lingered at the host stand and asked Abby or me what we did besides this, my answers always changed. "I'm going to study medicine," "I'm going to be an accountant," "I'm a model," "Haven't you seen me on that one TV show?" or "I'm writing a book" were among my favorites. It didn't matter what I said. All that mattered was that I wasn't a college dropout with a terminally ill brother.

Abby liked to draw hopscotches for us on the sidewalk, so we could get drunks to hopscotch as they walked by. If they were drunk enough, they'd tip us a buck or two for their good time. One time a man who had just finished dinner stopped to enjoy the hopscotch. He was from Chicago and asked if we had ever tried their famous deep-dish pizza. We hadn't. So he took down my address and shipped boxes of Lou Malnati's pizza to my house. Mom had the outside freezer stocked with the delicious pies.

When the managers weren't looking we super-glued quarters to the sidewalk and laughed when people tried picking them up without any luck. Tonight I was feeling down, so was hoping Abby had something planned for us.

"Liz is here tonight, so probably not much," Abby said. Liz was the only female manager. The other male managers let us get away with anything.

“Oh bummer. Great way to end my day,” I said. I flinched at how depressing that sounded.

“I was talking to Noel about Gavin. He said he had a story for you,” she said.
“You should talk to him.”

“You told him what?” I asked.

Before she had time to answer Noel came up behind us. He was a short man standing a little over five feet tall, about the same height as Abby. He was a server at the restaurant. We had never been friends. He did his job and I did mine.

“Abby told me a little about your brother,” he said.

I looked down at him awkwardly, and tried to search for something to do.

“Oh yeah,” I said. I started wiping down menus. “What did she say?”

“She told me how your brother was really sick, and how hard it was for you and your family. What does he have?”

I looked up from the menus. Explaining it was like trying to teach a foreign language I hadn’t learned yet.

“He has this really rare disease. It’s hard to pronounce. It’s called Aicardi Goutieres Syndrome. I haven’t decided if I pronounce it in a Spanish or French accent,” I said embarrassingly, faltering my words. “It’s this rare genetic disease that only fifty kids in the world have. It causes brain damage, ‘loss of atrophy in the brain’ is what Google says.” The information on the disease was little to none.

“So will he be okay?” Noel asked.

“I don’t know. Everyday is a guessing game and research project,” I said. “He’s four months old now. Ask me in eight months.” I chuckled a little.

I was acting like my dad. In eight months he’d be dead, or close.

“He’s just in a lot of pain and really sick. He’s in Hospice care so that might say something. I really don’t know.”

“You and your family are in my prayers. I thought I’d share my story with you. It’s not the same, but maybe it’ll help,” he said.

“Oh?” I said, going back to wiping down menus.

“I lost my brother,” he said.

I stopped wiping down menus and looked up.

“When I was nine my dad was backing out of the driveway and ran over my four year old brother and killed him,” he said. “My mom blamed my dad for years.”

I looked at him in shock. “I’m so sorry,” I said. I couldn’t imagine.

“It took many counseling sessions and two babies later to kind of move on. But you can never really. And through it all, somehow, my parents stayed married,” he said.

“In a way what happened brought my family together.”

I thought of Gavin bringing us closer together. I couldn’t imagine that, either. All he was doing was tearing us apart.

“You take a lot less for granted after something like this,” he said.

I believed that. But my brother wasn’t dead. Was I now the public dumping ground for really sad brother-death-stories? I hoped not.

“Sure.”

He pranced away, appearing relieved to have shared his story with me, like he had done some kind of good deed. I put the stack of clean menus back in the host stand and checked my phone. Mom texted me, “Not going to Kathleen’s.” I felt relieved.

The next morning I sat nervously in the salon chair. I was going to chop off my hair and donate it to Locks of Love, an organization that gave hair to children who have suffered from long-term medical hair loss. Abby, with similar long blonde hair, sat in a chair next to mine. I’d thought of the idea last night at work. My hair was something I could control. Chopping it off would liberate me. I could help save someone by giving my hair away.

“Are you sure you want to do this?” I asked. I ran my fingers through my hair.

“Yeah. Change is good,” Abby said. She smiled at me one last time before our stylists turned us towards our own mirrors. My stylist put my hair in a ponytail, then snip. She handed me the ponytail held together by my black rubber band.

“Holy crap,” I said as I held mine up for Abby to see in her mirror. She held up hers for me to see, too.

“We did it!” she said.

When I got home I felt proud, giddy even, but that feeling faded quickly. I opened the front door and looked past the foyer to the left: the living room we barely used, with the Indian patterned couches, was occupied. Sydney and a lady I’d never met sat there talking. The foreign woman was wearing all blue with a tight bun on the top of her head. She looked like a police officer, but she couldn’t have been. She was wearing dress shoes. Sydney saw me enter and gave me a secret wave, and a forced smile. I thought I

had grown up too fast because of Gavin's disease, and while looking at Sydney, I saw she had, too.

I wondered where Mom was. I walked through the living room and into the rec room with a TV that covered half the wall. Mom often called it the Devil. The rec room had turned into a second bedroom for Mom. Blankets and pillows covered the suede nude couches. Plastic syringes, bottles and plastic nipples were strewn across the floor. Mom used the plastic syringes to drip the medicines like liquid Morphine and Ativan into Gavin's mouth. Mom, in all black, was staring out the ash-covered window yelling on the phone.

"You need to get home now!" she said into the receiver. "I can't believe this."

She had to be talking to Dad. I looked at Gavin in her arms. He was shrieking. I put my hands over my ears. I wanted to scream with him.

The tricky part about his disease was that he looked normal much of the time. Whatever damage was happening in his brain was not completely visible. That was until a bad episode of the Monster came. After the Monster came, Gavin's motor skills decreased. He was a good breast feeder, but was getting worse because he was close to no longer being able to suck and swallow. I could also tell he was getting sicker because of his eyes. They often lost focus when looking at mine. He was slowly losing control of the physical movements he was born with. Mom feared the day he could no longer eat. She didn't believe in feeding tubes, and agreed if the day came she'd let nature take its course.

"Nice haircut," she said after she noticed me watching her.

“This is ridiculous! I’m calling Hospice and getting the woman fired!” she said and hung up the phone.

“Who was that? Who is talking to Sydney?” I asked.

“Your father,” she said. “Sydney is talking to a woman from CPS.”

“CPS?” I asked.

“Child Protective Services,” she said. “The woman came over right before Sydney got home from school.”

Child Protective Services? The words stung the tip of my tongue.

“What?” I asked.

“She came saying she’d received an inquiry or something; to come and make sure Gavin was safe. She said she’d just come from Danika’s high school, and was now here to see the baby and talk to Sydney,” she said. “I’m pissed off.”

The phone rang in her hand. It was Danika.

“Hi sweetie,” Mom said. “She asked you what?”

She hung up the phone and turned to me.

“I can’t believe that woman. The nerve. Danika said she pulled her out of class and asked her how she was feeling at home with a mom who was trying to hurt herself and with a brother in Hospice. Danika didn’t know Gavin was in Hospice. Now I have to explain to her what Hospice is,” she screamed.

“Does she want to talk to me?” I asked.

Mom began picking up Gavin’s medicines and milk bottles from the floor.

“No. You’re over eighteen. She said she doesn’t need to,” Mom grunted.

Yes she did. She needed to talk to me. She should want to. I'm the one who said Mom threatened to run away and drive off the Coronado Bridge or escape to the desert for a slower death. I turned Mom in. What she told me scared me. I couldn't fathom losing her to suicide. I would have to redeem the situation because I caused it. I felt nausea lumping in the pit of my stomach. Seeing Mom upset made my stomach queasy. I ran to the bathroom and hung my head over the toilet.

When I left the bathroom Mom was talking with Sylvia, the CPS worker.

"It was just dark humor," Mom said. "The baby is in such agony. But I didn't mean those things. I've no intention of hurting myself. I have three beautiful daughters."

She took a breath.

"I'm doing the best I can," Mom said. She looked down at Gavin and brushed her fingers through his hair and kissed his forehead.

"You seem to be doing an excellent job maintaining him," Sylvia said.

"You try it," Mom said.

Mom held out Gavin to Sylvia gesturing for her to take him. Sylvia's face went blank and she went on her way.

"That woman is getting fired. I'm making the phone call right now. No one ever comes onto my property scaring my girls like this!" she said to Sydney and me.

Dad walked in the door, holding his lunch bag, wearing a tie.

"What's going on here?" he asked.

"Don't pretend like you don't know. You did this," she spoke to him with pure anger. The look in her eyes was of a dagger. "We'll talk later."

She held Gavin in her arms and walked outside to get fresh air. The dogs and cats greeted her and rubbed up against her legs.

Dad turned to me, “Do you know what’s going on?”

“Don’t worry about it. Everything is fine now. It was just some confusion,” I said.

He put down his lunch pale and went upstairs to change, something he did every night after work, and each night he spent more time up there unwinding, doing whatever he was doing, avoiding Mom.

Sydney had been excused to her room. I wanted to make sure she was okay, she was too young and innocent to be in the middle of this. I went upstairs to Sydney’s room to measure my ponytail. Sydney’s room smelt of sweaty shin guards and was scattered with dirty clothes and *Twilight* books.

She was busy on the floor writing with colored markers on white paper.

I put my arm around her and asked if she was okay.

“I don’t want to talk about it,” she said. Sydney was sensitive like me. She had an awareness of others’ emotions. I doubt she had a clear idea of what was going on.

“Babe, do you have a ruler I can borrow?” I asked. I called her babe because it was short for baby, which I’d called her all her life because for a long time she was the baby.

“Yeah. Do you like your hair?” she asked. “It’s short.”

“I haven’t had time to get used to it,” I joked.

She went to grab a ruler covered with President's faces for me to measure my ponytail. It had to be ten inches for me to donate it to Locks of Love. Abby called earlier explaining that she had mailed hers off already.

"What are you going to do with it?" she asked.

I measured it and read the length: nine inches. I set the ponytail back down. An inch off. I had failed twice today. I had failed at helping my Mom by making things worse. She was the maddest I had ever seen her. I had failed at helping save a stranger. All I was left with was a heart of guilt and a hand full of hair.

I chucked the ponytail out of the room. "Nothing," I answered.

"What are you working on?" I asked.

She was writing on a piece of printer paper with a black Sharpee.

"A contract," she said. "For Daddy."

III.

The contract was for Dad, who seemed to be losing hope. It was a list of ten rules for Dad to sign, things for him to work on, like give Gavin a bottle, and help out around the house more. He was isolating himself further away from Gavin and from us. No one could handle Gavin. That was obvious when people offered to hold him for five minutes at the most before he started shrieking. Calming him down and comforting him was a hard practiced skill only Mom had. There was a saying someone wrote in one of the sympathy cards we got that said, "God only gives you as much as you can handle." Mom always taught us to believe in and love God and understand that life wasn't always perfect. It

wasn't supposed to be. But I knew now her faith was tested. I wondered how much she could handle.

Mom was a strong woman like Rosie the Riveter in the wartime propaganda poster saying, "We Can Do It!" She had been tested her entire life, endured, conquered and succeeded. She told me that her trick was this: "It's like waking in a dim hallway. There are doors and passageways you just don't go down. Keep your head straight and keep walking." Her trick was to keep walls up and keep moving.

Mom grew up in a lower class neighborhood on the outskirts of Chicago. She looked different than her sister who had black hair and olive eyes. She was a mutt, with tan skin, blue eyes and dirty blonde hair. Growing-up in a predominantly Black neighborhood, she lived in a small apartment complex and shared one phone. When she was five she and a girlfriend would walk down to the local liquor store to steal candy bars. The one time she got caught was when Buddy made her return and a pink folding chair she had stolen. He pulled her home by the ear after she apologized and made her bite a bar of soap for a minute. When she was in high school, her boyfriend dealt drugs out of her locker and she would drink screwdrivers on her walk to school. Her mom hated him, so when he got shipped off to war she dumped him.

When she was sixteen she started her first job at the local pharmacy. She worked there with her best friend Rob. On a winter's eve he went missing, and she was the last person to see him. Before he disappeared she was wearing his flannel jacket, developing photos. While developing some of her own photos she tore off the receipt and thought to throw it in the trash, but had a premonition – or clairvoyant moment – to save it instead.

She slid it into Rob's parka pocket. Just minutes before he disappeared he asked my mom for his jacket back, to meet with the "contractor" outside, the man who would be the one to rape, kill and murder him. The contractor would turn out to be John Wayne Gacy, also known as the Killer Clown; one of the most notorious serial killers of his time. He would dress up as a clown, strangle, then sodomize his victims, violently, then bury them in his home, leaving him to smell the decaying bodies of the boys he had killed. Because Mom saved that receipt, Rob was Gacy's last victim. The police were able to link the receipt to Gacy's home, which further led to the investigation of Rob Piest. I know this because Mom's name, Kim Byers, were the first two words in *The Killer Clown*, a book depicting the story of Gacy's capture. During the course of 1978 police found twenty-seven bodies in the crawl space of Gacy's home; the remaining six were found in the Des Plaines River. Mom had to be part of the trial, which troubled her, and still did. She had to confirm Rob's body, and relive, what she thought, would be the most haunting time of her life. As soon as she could, she left Chicago for San Diego.

Her second test would come in her early twenties, right after I was born, when she lost her mom to cancer. She thinks her Mom's spirit passed through me the night she died. We were all sleeping at Aunt Karylee's when all of a sudden I awoke with a shriek, Mom said. Karylee called within a minute later telling her that their mother had passed.

Nine years later, for her third test, she battled cancer herself. While she was in medical school and pregnant with Sydney, she found a melanoma growth between two toes on her left foot. I remembered the night before her surgery. Dad, Danika, and I sat

around her on the couch and painted her toes a beautiful, bright red. Dad kissed the toes and wept over them the night before they were to be amputated.

Throughout God's tests Mom kept good humor and never turned dark or cynical. She was open and honest in telling me stories about the day Rob disappeared. She learned to accept her Dad's new wife, Grandma Barbara. After the removal of her toes, she called her left foot the "claw," and told people a shark bit the two toes off. But something about Gavin's test was different. It was more complex, as the stakes were higher; many tests were involved. There was her test with Dad, test with faith, and test with her family, and the little boy she committed to give a happy life to. The black swans had now caught up with her, delivering her a tired face and saddened soul. She'd lost the humor that kept her strong through the rough times.

To take a break and clear my head I decided to go for a run around the golf course by our house. It felt refreshing, as leaving the house often did. I was alive as I ran. The crunch of gravel below my feet, sweat smoldering under my armpits, and fall air kissing my cheeks were all reminders I was alive. The path around the golf course that sat a half-mile from my home became another escape.

I pushed my heavy arms through the crisp air sloppily and stopped every minute or so to crack my back. I also knew I was alive by the jolting pain in my left knee, and the spot on my spine that stung in its curvature. But I didn't care. I was alive as I ran and similarly I was dying. I, like Gavin, would one day be a victim of death.

While I continued trotting like a gimpy old racehorse with the 1.5-mile marker in the distance, I wanted to stop. I wanted to give up so badly on this run. The course was 3.3 miles in distance. I could have run the whole way, but something inside me, like it often did, urged me to retreat.

“Turn around. You’re tired.”

Then my conscious assured me that pushing on would yield a better state of mind. I couldn’t stomach another failure like yesterday.

The golf course’s clubhouse and a small pond marked the halfway point on the trail. At this small pond abandoned ducks and geese gathered of all colors and sizes. I had memories of when we moved to Bonita when I was in fifth grade. Mom took us here first. We brought stale white bread and tore it off in pieces and tossed crumbs to the hungry birds. I was especially afraid of the geese. They used to snip at my toes. But the ducks I could only love. When I was little I daydreamt of one day having a duck to call my own. I dreamt I’d put it in one of those flowered plastic pools Dad bought at the Home Depot.

I was going to run all the way around I thought to myself, taking my first leaps onto the grey pavement, through the parking lot, to the path continuing on the other side.

“Hey. Hey you!” I looked up and noticed a huddled group of middle-aged men standing with their visors, khaki shorts and beers next to their golf cart waving me down.

They were hitting on me, I thought.

I pulled down my shorts and pulled up my shirt and made a disgusted face towards the ground as I run past them. They were around Dad’s age.

“A baby duck is hurt over here. We almost ran it over. And don’t know what to do with it,” one man said from the crowd.

I stopped running. I walked over, to see if this was just a cheap pick-up line or a real duck was in need of my savior.

At first I didn’t notice, but then I saw her, huddled behind one of the man’s legs. She was fluffy like a baby chick, dirty brown, about the size of my fist. She looked helplessly weak. If I held her too tight she would crumble beneath the pressure of my fingers. I examined the abandoned duck and noticed her left eye.

“She’s missing an eye,” I said.

The golfers circled around me.

“In fact she is,” one of the men added.

“Who has a towel?”

One of the men handed me a white golf towel. I wrapped the duck tight in the towel and clutched her close to my chest. I could tell she was a She by her coloring. She was a female mallard. No dark green head.

“I’m taking her with me. She’ll die out here. I can’t leave her to die.”

The men looked at me, shocked.

“You are a good person. The man upstairs will be looking out for you.”

I smiled and walked the 1.5 miles back to my car to drive the half-mile back to my house. I kissed her head. She smelled of dirt and car oil, and soft as a new stuffed animal.

“Messenger, I’ll call you.” And that was her name. She was a message from the man upstairs that somehow and somehow there was hope. God was on my side.

I walked through the garage into the backyard. Everyone was in the house but Mom. She was out by the white horse corral watering the trough. The air smelled of wet manure.

“What’s in your arms?” Mom asked from the hill.

“A baby duck,” I yelled back.

“A duck? What am I supposed to do with a duck? I’ve got enough people and animals to take care of.”

“It’s my duck you don’t have to do anything.”

“No, no. Bring it back to where you found it. You guys get excited for a minute then forget about them.”

She pointed to the coop where the chickens and rabbits lived. She had a point. But this time was different. I told her the story about finding it, and how it was missing an eye. She was the one who led by example – always saving cats, dogs, and birds, bringing them into our home until they found their owner or were healthy enough to fly off on their own.

“Let me see.”

She walked over and examined Messenger. I thought saving something might be good for her, too.

“Well let’s set up the cage,” she said. It only took her a second of holding the fluff of brown feathers to be smitten by her.

“Yes!”

She went inside the garage to grab the dog kennel. I sat Indian style in the spiky grass, letting Messenger explore her new world. She waddled a foot away before running, and flapping her tiny wings back to my lap.

“I wonder when we can put you in the pool,” I pondered.

Mom came back with the dog kennel.

“Let’s put some hay in it,” she said.

I handed her Messenger and walked into the shed to grab some hay. I loved the earthy, rustic smell and feel of hay. Roxy, our brown Calico, was sleeping on one of the old saddles. She jumped down and flirted with my feet and rolled on her back. I scratched her belly, soft and warm. Roxy was my favorite cat, next to Sweetheart who died when I was in middle school. She was a Mouser, as Dad called her. She was a great hunter and one day killed a rat that had eaten rat poisoning. That was the only cat Dad cried about.

“What are you doing in there?” Mom interrupted my thought. There was something rejuvenating about being in the backyard, away from Gavin.

“Come out here. You have to see this hawk,” Mom said.

She tilted her head up towards the trees and made a screeching noise. I loved that about her. She loved birds, animals, and nature. Whenever she saw a hawk she thought of Gavin, which meant battle hawk. So did I. I even had a hawk sticker on the bottom corner of my laptop. It was fading, and peeling off, so I covered it with tape. Whenever I opened my computer I saw it, and pressed it down with my thumb and thought of Gavin.

We were finishing up Messenger's temporary home, when Danika opened the back porch door.

"Mommy, Gavin is up. He is crying," Danika yelled across the yard.

"Tell you father," Mom shouted.

"He said it was your turn."

Danika went inside. Mom turned to me. "I get my alone time for thirty minutes. That's it? He gets to leave everyday."

She stomped her mucking boots back towards the house. I scrunched my nose. I didn't want our moment to end and I was mad – why couldn't he stop him from crying? He acted as if he didn't care. Maybe he was afraid of Gavin, too. But it didn't matter – he was his dad. I gritted my fingernails into my palms.

VI.

Dad was alone. This was my chance.

He wore his faded blue jeans Mom bought him for Christmas a few years back and a Valhalla soccer shirt. His feet were kicked up on the brown leather recliner. On the side table next to him rested a bottle of Coors Light. Sports announcers echoed from the TV. I opened the glass doors and entered the living room. I could hear Gavin crying and Mom cooing him, pacing around the bedroom upstairs. The outer corners of my mouth quivered. I loved Dad, he was someone I had always looked up to, and it pained me to feel angry with him, but I did. I was angry for us, for Mom. I dragged my feet across the

stained cream-colored carpet. The stains were from Goldie, our golden retriever, on her last days of life. Mom scrubbed for many days, but it didn't matter. You could still tell.

“What are you doing?” I asked.

“Watching the Padres,” he said, still facing the TV.

“Why aren't you upstairs?”

“Mommy's up there.”

“So. Why aren't you?”

“I'm watching the game.”

I stood in front of him, blocking the TV.

“You never hold him!” I said, letting my voice louden.

“Yes, I do. You just don't see me.”

“You don't.”

“Okay, Pokey. That's enough,” he said, ushering me away with his hand.

I stayed put. “You don't know what it's like,” I said. “You don't know. You don't do anything.”

He laughed. “You serious?”

I paused. “I'm not the only one who thinks this.”

He called Mom into the living room and she reluctantly came in after Gavin was calm. She sat on the couch, Gavin braided into her arms; Dad sat in the recliner; and I sat on the ground with my arms wrapped around my knees. I clutched my knees rocking back and forth, rubbing my head on them. I had broken the rules, the line between parent and child.

They both sat there, once in sync, now broken and out of tune. Mom, with matted hair and tired cauliflower-blue eyes went first.

“I’m drowning, Sam. In sorrow. In loneliness.”

She wiped her eye with the sleeve of her white knitted sweater.

“I’ve been standing alone for too long and it’s breaking me down deeper into this dark hole that is now my life.”

She sniffled. She looked lonely in the far corner of the couch. I felt like an eavesdropper on this very adult conversation about feelings. I wanted him to get up and hold her, but he didn’t.

He coughed, clearing his throat. “I have so much responsibility. Right now I am the sole provider for our family with you home. It’s a lot of weight on my shoulders. On top of Gavin’s extra expenses and you out of work.”

We thanked him for this. But something was missing.

“Daddy, you are doing everything you can. Except one thing. Love. I don’t feel the warmth of your love.”

He jolted up, grunted, and shoved his hands on his head. His face was red and angry. “Is she just the tip of the iceberg?” he asked Mom.

“Sam. Friends and family say the same thing. You are disengaged from Gavin and us. I’ve been in this game alone, waiting day after day for you to come back. But it’s been too long.”

He turned to me, “Courtney, get out of here!”

He only called me by my name when he was mad.

“No!” I said. “Not until things are better. I’m not leaving this room.”

“Let her stay. She got us in here, facing each other,” Mom said.

Since the beginning of their marriage, they made an oath. It was this: the best gift you can give your child is a good marriage. And this, this spectacle in the rec room, was everything but. They spent the next hour talking. Mom shared how angry she was at him for hiding in the garage, and resisting giving his baby a bottle. It was as if Dad was putting off the inevitable, living in a delusional land of work and existence. Dad talked about how hard he was working to support the family, financially, and acknowledged how he had failed to understand her grief and the difficulty of staying home with Gavin all day. At the end of the conversation Dad had decided he would learn to give Gavin a bottle, even if it would be difficult because of how irritable Gavin was. I, on the other hand, felt a new truth. Perception and grief were skewed. Dad wasn’t just ignoring us. He was doing it as a way of surviving grief. We all grieved. Not just me. Not just mom. All of us. I made the mistake by thinking one parent’s grief was stronger than the other’s.

When the room calmed down, Dad decided to end the meeting with a story. Danika and Sydney had overheard the raised voices, and were now in the room, too.

“We have to stay hopeful,” Dad said. “Do you girls know the story of the Osmond family?”

“No,” we said.

“They were a family of fantastic musical performers, performing internationally with over 100-million records sold. But they weren’t always that way. The first two

Osmond children born were born hearing impaired. They were deaf. The parents were devastated. The doctors told them to give up on conceiving again.”

“And?”

“And they ended up having seven more children. The children first started out performing to raise money for necessities like hearing aides. Soon enough the family turned into a multi-millionaire music legend.”

We nodded our heads, and Mom and Dad made up for the time being.

I couldn't lie, though, his example was a little random, and when I would ask Dad months later, again, about his example, he wouldn't recall telling it. Maybe that's what hope was: fleeting bursts of inspiration, possibly unattached to reality. A quick spiritual high. Even if I could not save Gavin, I had saved Messenger. Things were not completely hopeless. I had thought about transferring to UC San Diego because I didn't know if I would be able to return to Santa Barbara in the new year. My family needed me.

Later that night Mom got a call from Laura, her old office manager. She suggested throwing Gavin a benefit, to raise money for him and create awareness about his disease. It would also be a chance for many friends and family to meet him. It was difficult. To introduce someone to a baby who was terminal. But, we decided to move forward with it, and spent the next two weeks planning, organizing and setting up Gavin's Benefit, a night all for him.

V.

On the first Saturday in December, Dad pulled out of the driveway towards the freeway. The car was full and silent, except the noise from windshield wipers brushing away rain. I moved uncomfortably in my seat, adjusting my dress and fiddling with a camera. I was uncomfortable and hot and angry. But I couldn't lose my mind to my thoughts. Outside, I noticed a rainbow had appeared over the mountain. I rolled down my window and took a picture; inhaling the smell of fresh rain.

“Look at the rainbow,” I said.

Everyone looked.

But the moment was interrupted by my brother's crying.

“Gavin, Shhh,” I said, annoyed, trying to calm him, rubbing his shoulders and legs to ease his muscles. His limbs tensed when he cried and if I didn't rub them, his legs would do what Mom called “shaky leg.” During shaky leg his legs seized, and I held onto his feet until it stopped. His cries waned while Mom took over rubbing his leg.

“Let's play some music,” Mom said in her baby voice. “Gavin loves his music.”

“Put on Channel 93.3,” Danika, suggested from the other side of Gavin's car seat, in the middle row of the car.

“I want to check the game,” Dad said, turning the radio to AM sports.

“Gavin doesn't like sports,” Sydney, chimed from the back row. “That's not *his* music.”

The fuzzy AM station went out, and Mozart's composition, *Requiem*, came on. Gavin was quiet. We were on our way to Gavin's Benefit. In part, it was going to be a

celebration and baptism, but also a fundraiser. The money donated was for Gavin's foundation. It wasn't for college or anything like that; it was for medical expenses. And God help him – funeral expenses. Gavin, my only brother, was dying. And here I was angry and annoyed with him for crying – out of pain – as the disease destroyed and deteriorated his brain, he became more irritable. So he cried. And internally, so did I. But no one was allowed to see that.

I closed my eyes. When I opened them again the rainbow now had a twin.

Rainbows are magical and beautiful – but also symbolic. On the day of my parent's wedding a rainbow appeared when they walked out of the church, after saying their vows. Mom told me it was representative of Dad's mother watching over them, sending her blessing, since she died when he was eleven. When Mom's mother died a few weeks after I was born, they decided to believe the same for her. A double rainbow meant two mothers' blessings. I looked to the front of the car. My parents were holding hands, wearing their gold bands. They must have seen, too.

We pulled into the country club as the sun began to set. The parking lot was already half full. Women walked around in semi-formal dresses with heels and the men wore nice shirts and suits. I made sure not to lock eyes with anyone. If this ever was a secret between my family and close friends, the secret was out. Everyone knew.

I wasn't the only one nervous. Mom's eyes darted across the parking lot.

“Sam, I need to have some sort of home base. Gavin can't be around all these people the entire night. He'll get Monstery.”

Monster was the name Mom attributed to Gavin's disease when it was at its worst. Monster sessions consumed Gavin with wobbly, unfocused eyes, an upset stomach, high fever, jitters, and seizures – all in which he would not cry – but shriek – louder than any opera music could cover up. It was like someone was torturing him from the inside out – almost demonic.

“Laura set up a room for you over there.” He pointed to a corner hotel room, across the lawn.

“I'm coming, too” I said. I was not ready to partake in small talk about dropping out of college to be home with my family or give the eldest sister commentary on Gavin, who had been in Hospice for a month now.

“If Courtney's going, I'm going.” Danika added.

“Okay. Sam, I'll take the girls. We will meet you in there. Come on Syd.” She started walking towards the room. “Can someone grab Gavin's diaper bag?”

I turned on the lights in the hotel room, our hide out. A gift basket full of pretzels, crackers, cookies and beverages sat on the bed, and there was a rocking chair in the corner for Mom and Gavin. I went to the bathroom to look in the mirror, prepping before heading to the banquet hall. Danika followed. We gave volume to our curls and applied lip-gloss. I fixed my bra, maximizing my cleavage. Danika tried to copy but she had less to work with. I secretly hoped I'd meet a cute guy. I kept the prince charming dream vivid and constant. If someone could save me from the war in my heart – then somehow – I would turn out all right.

“Come on you guys!” Sydney yelled from the other side of the closed door. “Mommy needs to use the bathroom.” Sydney, at only ten, was the caretaker of my mother when the rest of us abandoned her – including my father who normally a lovely, caring husband – rarely talked to her or us or Gavin.

“Relax. I’m coming,” I said.

I walked out, momentarily forgetting where I was. Then like it often did, reality set in like buckets of sand, suffocating. I looked at Gavin, rocking in Mom’s arms in the rocking chair, and my shoulders and chest went from confident and straight, to slouched and pouty. The breast pump rested next to her, which she now had to use quite frequently because Gavin had lost the ability to breastfeed on his own.

“How’s he doing?”

“Tired. A little cranky.”

“Well, he looks like an angel,” I added and bit my lip. As far as I could remember, I hadn’t yet cried in front of Mom. It had been a month now since I withdrew from school – but looking at him – so fragile, so pure, I fought the tightness building up around my mouth. Mom had changed him into his white gown for the baptism. The cloth hung past his toes, and sat loose on his thin body.

I could not pinpoint the feeling for this so called celebration. The Benefit, something we’d planned for weeks, wasn’t like a complete loss like death or a giddy celebration like a wedding. It was something caught in an unfamiliar place. We were celebrating death to come.

“Want me to hold him?” I asked while opening a bag of pretzels to snack on.

“That would be great,” she sighed. I hated to see her this way – trapped.

Mom quickly swigged a sip of her Diet Coke, stood up and offered me Gavin.

Gavin was always attached to her. He became fussy when others held him. Mom was the only one he tolerated. I put my arms out and accepted him. I was afraid he would start shrieking, feeling uncomfortable in my arms, so I took a seat in the warm rocking chair and stared into his wandering blue eyes, trying to connect. He stared back at me, silent. I had been angry with him so long, for being sick and on Hospice. But something about this moment, this night all for him, I felt a shift in my heart.

“I love you, baby,” I said. I kissed his forehead and smiled.

He flickered his eyes back at mine.

The banquet hall where the Benefit was being held was decorated with rich Christmas greens, whites, and sprinkled with baby blues. The room had the capacity to hold over two hundred people. Tables stacked with plastic-wrapped gift baskets for the silent auction lined the room. There were beachside getaways, rounds of golf, jewelry, restaurant gift cards, massages, et cetera. Guests signed in at the front of the room, next to a blown up picture of Gavin when he was a few weeks old, the picture from his birth announcement. I had taken that picture while he was sitting in my lap during those early days when he could still suck on my bony knuckles. But now, since he lost that mobility, I missed that closeness. On the right side of the room was the bar, and in the front of the room was the stage where Gavin would be baptized this evening.

Carrie, the benefit coordinator, approached me, dressed in a swanky black dress suit. It made me feel wrongly underdressed. I was wearing a gold dress (kind of cheap) with a horn necklace and boots. But then I remembered she was probably married and thirty, and I was barely twenty and didn't know a thing about love or relationships or appropriate attire for your brother's funeral benefit – in which one was also trying to attract a potential mate.

“The centerpieces look great,” she said.

I thanked her and went over to the first table to examine the centerpieces I had spent last evening setting up. During the time that went into planning this evening, I had wanted to help. So I was assigned to this. Carrie and I had decided on a few different styles. The tables had white tablecloths overlapping long forest green ones. Each table had various sized vases which held white floating candles in tall, fragile cylindrical vases; while thicker, taller candles waded in shallower vases. We used white stock flowers that smelled like warm honeysuckle, and stained glass rocks of various blue and crystal colors. Mirrors were placed underneath the vases, and more small white candles and the extra stained glass rocks to decorate the tables. For months, things felt out of my control. This project gave me a purpose – opportunity to feel accomplished.

Cocktail hour had begun. The room was filling up. I went to the bar.

“Can I have a glass of Chardonnay?” I asked, placing three dollars in his tip jar.

The bartender was handsome – short brown hair, a foxy smile, but maybe too old.

“Do you have ID?”

“No not on me.” I smirked. “I’m Gavin’s sister. Part of the family putting this on.” Without hesitation he poured me a heavy glass. “Thank you.”

I walked over to Mom, Danika, and Sydney who stood with Gavin outside on the patio. “Nice view,” I said. The sun was setting over the golf course. Oranges and reds brushed the sky.

“Hey, you are not old enough for that,” Danika said, pointing at my wine.

“I’m old enough tonight.” I smiled cheekily and went to check my phone.

No messages.

“Hey you,” Laura said. She had been a friend of Mom’s for years. Laura was Mom’s office manager when she still worked as a physician at Sharp Memorial. Now I think it had been – what – almost 7 months since Mom had been out of work. She had gone on bed rest 2 months before Gavin’s birth because her pregnancy was high risk – she was forty-seven when she was pregnant with Gavin.

Laura was dressed in a fitted black dress, with her blonde hair resting neatly on her shoulders. She looked like an older version of Barbie.

I gave her a hug and thanked her for putting so much work into this night.

“Should be a good night. We’ve raised almost forty thousand so far in donations. After people bid on the silent auction we should reach at least fifty.”

“That’s great. Really.”

We continued chatting, with other people coming in and out of the circle. In the back of my mind I was excited that Gavin was raising money. But I was also disgruntled by my thoughts. What was in it for me?

The room was still. Dinner had ended, and the last plates were being cleared from the tables. Gavin, in my mother's arms, was the center of attention. In the front of the room stood Mom, Dad, the pastor, and two witnesses: Michael Evans, my mother's longtime friend and spiritual guide, and Dave, Kathleen's husband, standing in for her. For once Gavin seemed at peace. He wasn't making any fuss. The pastor recited some words and sprinkled water over his head, brushing it through his hair. Gavin, like I, was baptized Methodist.

When the holy water was sprinkled across his forehead I knew that at that moment we had let God be the leader in Gavin's life. We remained his physical support on Earth, along with everyone else present. I admired a portion of a quote the pastor read, "Love knows no boundaries, love has no end." It was my new mantra for Gavin. He was capable and deserving of God's love – and my own.

After the baptism, Michael Evans invited Dad to speak. In one hand he gripped his speech. In the other he held a toy, one I remembered from childhood. It was a wind up toy that played an instrumental version of "Over the Rainbow" from *The Wizard of Oz*.

"Good evening friends and family. Thank you for coming out tonight to support our special boy, Gavin." He looked at his boy. "I wanted to start off by sharing the story of this toy. This toy has been passed through the family for twenty years. The girls enjoyed winding it up when they were younger and singing along. Now it is Gavin's turn. I'm surprised the thing still works." The crowd laughed. "But I am glad it does. This is one of the few things that ease Gavin when he is in tears and in pain. When he hears the

music, he stops crying.” He turned the knob, and held the toy up to the microphone. The room quieted. People cried.

Dad was good at being sentimental.

I looked at Gavin, across the table from me, cradled in my mom’s arms, still in his beautiful baptism gown. He was smiling.

Dad continued, “Thank you for showing your love and support tonight. We can’t give Gavin a normal life, with Boy Scouts and T-Ball, but we can give him a comfortable one, with lotsa love.” His cheeks flushed red; his eyes pinched. “Huh, Bubba?” He wiped his eyes. “Thank you.”

The room clapped. The MC took back the microphone.

“Thank you, Sam. Is there anyone else who would like to come up and say a few words?”

Chuck, my old softball coach raised his hand and went up. After him, Alfredo, an old soccer coach went up. The people who went up to speak were random. They didn’t know Gavin. Where was family? Close friends? I looked over to Aunt Karylee, sitting next to Mom.

“Is there anyone else?” the MC asked.

I could not escape the words Aunt Karylee was mouthing to me. She wanted me to go up and speak. I glanced to my parents. Dad was standing behind Mom with his hands resting on her shoulders. She sat in the chair in front of him holding Gavin, attached like a barnacle. They were nodding for me to go up to the podium. *What?* I looked behind to see if there was someone else. Couldn’t be me. This was not planned.

Dad had weeks to plan his speech. How was I supposed to go up there and say something moving? My speech would be unmoving, disorganized. I had never given a speech. But, the speech part of the night was about to end, and the slideshow would come on, and that would be it. I would feel guilty, I knew, for letting the speech section of the Benefit be forgettable. The people who spoke, except Dad, were crap. Aunt Karylee must have thought that, too. But why me?

Something inside, that voice, said, *Go*.

I told myself, *Okay, Courtney, you can do this. This is easy. All you have to do is be honest and speak the truth*. When the MC was about to move on to the slideshow, I stood up and walked to the podium. My heart was beating. My brain was racing, outlining in bullet points, and bolding important words I must say, all the while panicked that I wouldn't be able to speak at all. I took a deep breath, and stood behind the podium. I did that whole mind game of picturing the room in their skivvies. But nothing. Everyone was still clothed. Then I just smiled, and tried to lock eyes with as many people as I could. Like some weird eye trance. What kind of junk was I pulling?

I spoke.

If you asked me exactly what I said in those first few minutes, I couldn't tell you. I couldn't remember. I know I spoke of a few life lessons I had learned. I repeated my father's lesson, "Always try your best." I must have heard those four words a million times growing up. I explained I had learned that there is no other way. You have to always try your best. I also spoke of Mom's faith that, "Everything happens for a

reason.” And although the therapist told me, “Shit happens,” we had to have hope that at the end of this dark tunnel there would be light.

Then I remembered. By the end it was easy.

“I know we will get through this. Perhaps such special people were blessed with a special child because they could do it,” I said.

I could hear the sniffles coming from the audience.

“Take a moment to look around,” I said. “My family is surrounded by love. Without everyone here tonight, and without everyone who has been supporting us since we found out about Gavin’s disease, we might not have been able to come this far. There are no words to describe my family’s gratefulness. So thank you.”

The energy in the room exploded.

People stood up and clapped. They actually stood up. I looked at my parents and Aunt Karylee. She was giving me two thumbs up. Dad was grinning and Mom said, Way to go, honey.

I was rushed with adrenaline. I took a seat. My armpits had sweat stains, but I didn’t care. Dad came to rub my shoulders. Danika and Sydney gave me a hug. Abby, my high school friend, came over to my table and pulled my hair, “Good job, Corny.”

The lights dimmed and the picture slideshow came on. There were pictures from June, Gavin wrapped in a blue baby blanket, the month he was born; from July, a happy baby in Sydney’s arms, before he got sick; from August when he still looked normal, but was sick inside; from September until now, head shots taken from Mom’s cell phone, the moments in between the waves of sickness. I was in some. There was one of Gavin and

me, the first week he was born. I have his cheek up to mine, smiling. I was happy. Now, I wanted to be happy again, to fully embrace Gavin in all his disease. And after tonight, seeing Gavin through the eyes of his fans, of the people who loved him, who were fighting with him, with us – how could I not be happy again? Gavin’s human experience was going to be short, but it was going to be worth it. I looked around at all the lives he’d already touched by in his five months. I was happy, almost proud, to be his eldest sister.

After the slideshow and raffle, people got up. Michael Evan’s Jazz band came on. Tables were moved to the back of the room to create a dance floor. There was a line at the bar. I stepped outside to check my phone. The cold November air gave life to my cheeks. Tariq had called.

He was my coworker and one of the few people I felt comfortable talking to about Gavin. He joked about wanting to kiss me, but I saw him as just a friend. Fantasizing about dating and actually doing it were two different planets. He still lived on Planet Normal and I lived on Planet Sisters of Dying Babies.

I wondered if a real man could like me if he knew about Gavin. Not just like me, but also really like me, marriage-material-like-me. I wondered if his disease made me less desirable to make babies and create a family with. Because there was a testable possibility I was a carrier of AGS, too.

I didn’t call him back. I was too busy relishing the evening.

Back inside, I stood in line for the bathroom. The walls were covered in paintings of sailboats and seashells, and smelled of lavender. A group of three women I'd never met entered behind me.

"You were great up there."

"Thanks," I said. I was shy.

"Are you single? I have a son who would love to meet you."

"No. You would like mine more. He flies planes."

"I wish my son was single."

I stood there like a dumbstruck dog. They were all talking to me at once.

"Yes. I am single."

"Wanna see a picture of my son Chris?"

I must have looked confused, because the most aggressive one emerged, and introduced herself, "I'm Debbie, I used to work with your dad. I knew you when you were this high." She put her hand near her hips.

"Oh yeah, I remember." I lied.

"You are beautiful, intelligent, and funny. My son is going to marry you."

I blushed.

"Anyway here is Chris. He's in the Navy." She showed me a picture on her phone.

This stuff didn't happen to me.

"You want me to call him? Set you up on a date?"

I was on the edge between adolescence and adulthood: that awkward place where you were still the kid, but trying to figure out how to fit in with the adults.

I was flattered, but not sure how to react. There was a saying that I learned in high school that reminded me of this moment. Guys see girls in three different ways: ones that are relationship material, ones they just want to have sex with, or ones they wouldn't touch with a ten foot pole. For the longest time I wanted to be seen as the first. Maybe this was part of my pay-off.

Nat King Cole's, *L-O-V-E* came on, blaring from the jazz band. Family and friends filled the dance floor. People from all different ethnic backgrounds and ages were fearless with their dance moves. Abby and girls my age got low. The elderly swung their hips and snapped their fingers. Couples twirled. Circles formed, hips bumping, voices humming. Even Gavin had a nice time having Laura dance and twirl him smoothly across the floor. His gums peeked through and his eyes shined with brightness. As I took part and watched, I felt as if I was in one of those movies where friends and family dance after a wedding, while the credits roll. It was a time where everyone put everything behind them and just danced. I smiled.

Through my smile I felt a trembling hand gently grab my elbow. She did not think I knew her, but I knew her quite well. It was Alma, one of Mom's friends who never stopped believing that Gavin would see past his first birthday.

"Sometimes God sends angels down from heaven in the form of babies." She looked over to Gavin, glowing. "I think Gavin is one of the few."

Chills ran across my arms. I wasn't sure how to believe her or what to think. But I did believe Gavin was sent here to teach me something.

Part Three: Winter

I.

The high of the Benefit had dulled and as December was moving along, I had to face my swiftly approaching decision. I hadn't decided if I'd return to school. I tried persuading UCSD to let me in, but they said no. Part of me was afraid to face people at UCSB because I was afraid they'd judge me or my brother or my family. We were no longer part of "normal."

Dad went to church last Sunday. He goes to a Christian Science church. I didn't know anything about it except that it stemmed from Christianity and that traditionally, did not practice medicine as a form of healing. So I looked it up. A woman named Mary Eddy Baker, in 1879, founded the Church of Christ, Scientist. Growing up, her parents emphasized the presence of God in everyday life. In her mid-forties she fell on an icy road and suffered from internal bleeding. She was expected to die, but claimed to experience miracle healings of Jesus Christ from readings from the bible. She spent the rest of her life examining and studying the bible for miracles similar to her own.

I tried to picture Dad going to church every Sunday. Most days he went with his college friend, Doc, and other times alone. I tried to picture him kneeling at an altar, praying. I wondered what he asked for, what he hoped for.

When he walked in one Sunday in his buttoned church shirt I asked, "How was it?"

"It was good," he said. That was the extent of it.

"Why do you go?" I asked.

“Even when I feel there is no hope left, I have to pretend there is,” he said.

I sighed. He waited for me to say something, but before I could Mom walked in the room. She entered from outside. Her eyes met his. They seemed to glow. Recently, Gavin had been in okay spirits. And on December 5th Dad had successfully given Gavin a bottle. Church must have helped break or heal something inside of him.

“What are you doing?” Dad asked me, when Mom whisked off to the front yard to water her flowers.

I was reading. To escape the veracity of death, I found books – various kinds of books. Books that made me think deeply about the world and myself, books that enlightened me, entertained me, and even brainwashed me a little. It was all in good fun. At the moment, however, I held a book I found on the counter where Dad meticulously placed his cell phone, wallet, and keys everyday. Next to the keys was *Rich Dad, Poor Dad* and the one that sat next to it was *When Bad Things Happen to Good People*.

“I’m reading your book,” I said.

“Oh yeah,” he smiled. “A friend at work gave it to me.”

His answer meant he wasn’t going to admit he read it. The title had a tinge of self-pity – the question we all asked ourselves, but not out loud: Why Me?

It had been the sole question, the foundation of my growing grief that rooted in me like a tree, hardening my blood with its powerful origins. But we were all too proud, too strong to succumb to the pity. Every one of us had the spirit “to never give-up.” It was in our core as athletes. Dad was a swimmer his entire life, competing in the Junior Olympics in freestyle and butterfly. In the first years of my parents’ marriage they

coached at Granite Hills high school – she the head diving coach, he the head swimming coach. I grew-up to compete in swimming, diving, and water polo. The snack stands, the warm fuzzy parkas, the Ugg boots, the smell of chlorine, the greenish color it turned my hair were all things nostalgic of my second childhood home.

Danka and Sydney, however, were soccer stars. I'm not sure why – but I think it was because Mom and Dad stopped coaching once they got Real Jobs. Suburbia had a plethora of green fields and was a little lackluster when it came to pools.

When Bad Things Happen to Good People was an off white color with a burnt red border. I flipped open the book, thumbing through the pages. The author was named Harold Kushner. He was a Rabi and spoke much of God. He caught my attention in a similar fashion Elizabeth Gilbert had, whose book, *Eat Pray Love*, I picked up at Borders, where I hung out in the evening. I didn't look into fancy literature to give me the answers. I picked up self-help books. And others like *Skinny Bitch*, a book on veganism, *Mr. Maybe*, an indulging, unpopular novel. I checked my horoscope. And now, for the first time, a religious author.

He opened his book with:

This is not an abstract book about God and theology. It does not try to use big words or clever ways of rephrasing questions in an effort to convince us that our problems are not really problems, but that we only think they are. This is a very personal book, written by someone who believes in God and in the goodness of the world, someone who has spent most of his life trying to help other people believe, and was compelled by a personal tragedy to rethink everything he had been taught about God and God's ways.

I read on. He had a son named Aaron born with Progeria, a disease that inflicted rapid aging. Aaron would not live like a normal boy would, much like Gavin. Aaron died when he was fourteen.

An excerpt that stood out, one which was less slight than, “Everything happens for a reason,” was when he said: *God sends such tests and afflictions only to people He knows are capable of handling them, so that they and others can learn the extent of their spiritual strength.*

I let it sit with me. I focused on two parts. The first: *They and Others*. Maybe my family was an example for others, that we weren’t just staying strong for ourselves, but we were doing it for, perhaps, the culture. When the easier choice could have been to let Gavin stay in a home, we said, no, we would persevere, no matter where it took us. The second part: *Spiritual Strength*. What did that mean? Our spiritual athleticism? I imagined my soul traveling to some other, higher place while I was asleep. I imagined it hovering over a strength-inducing cardio machine, working out. I imagined my soul wearing pink neon gym outfits and knee-high tube socks. I thought about how far could one go, believing that this was all meant to be, or maybe accepting was the better word. Accepting that Gavin’s disease was meant to materialize.

I didn’t speak of my relationship with God, but I had faith in Him, a higher power – something far more in control that I could ever be. With our busy lives, my family stopped attending church except on Easter and Christmas. However, Danika and I had grown-up in Sunday school when we still lived in Imperial Beach and attended a

Lutheran church by our house. I'd also gone to a religious preschool. My faith continued to exist through prayer. Mom taught me a simple prayer when I was a little girl, and I had carried and evolved that prayer through my adolescence and young adulthood. It stemmed from, "Now I lay me down to sleep, I pray the Lord my soul to keep, while the Angels guard me through the night, and keep me safe until morning light. Amen." The original, which I detested at four years-old was, "Now I lay me down to sleep, I pray the Lord my soul to keep, If I shall die before I wake, I pray the Lord my soul to take. Amen." It detested it because it was negative. I was not going to pray each night about death, so Mom gave me the one using the Angels, which I admired much more. I had witnessed prayer work before, when Mom battled Melanoma. And when she was healthy again, she continued praying. Each morning with coffee she read her Daily Word, a small prayer magazine that could fit in a pocket. I prayed every night in bed once the lights were out, and before dinner.

There was not a time in my life where I cannot remember praying. Often times, especially in my younger years, I remembered hiding it. At a friend's sleepover, out to dinner with another family, or even sharing a bed with my own sisters – I felt it was a sacred ritual I had with God. I also feared I would be teased for being weird or different. The only time we prayed together was at the dinner table. Every night growing up, except for take-out Fridays (which meant no cooking or cleaning for Mom and included Carne Asada burritos), my family and I prayed. Friends and family who ate dinner with us said the prayer with us. We all held hands, and usually Mom, Dad, or I would start the prayer, "Say grace. Say grace. God is good. God is great. Thank you for our food. Amen."

Squeeze!” At squeeze we’d mightily squeeze each other’s hands. Friends I brought over would laugh, and learn the simple hymn by heart – and eventually embrace the cheesiness and chant it with us. Dinner table conversations were something I realized, now, I took for granted before Gavin’s diagnosis. Mom and Dad would always ask us about our day; we talked about school, sports, and joked around. The conversations we had were positive, upbeat, motivational – cathartic. Dinners grounded me. Missing dinner was considered rude. Answering the phone during dinner especially, unless it was Grandpa Buddy. Now, when we had dinner, it was interrupted Gavin’s fussiness and melancholy. What I would give to better understand the inner workings of my heart and soul. Maybe one of my other books had some answers.

*

In the true story, *Tuesdays With Morrie* by Mitch Albom, Mitch meets with his old professor, Morrie Schwartz, for their last class together. Morrie is dying. Mitch is the only student. The subject is life. Their meetings are as Mitch calls them, *a desperate attempt to steal something from death’s suitcase*.

In each of their meetings they discussed the meaning of life and it’s greatest lessons – because the closer you were to death, the closer you were to life. I wasn’t dying but I felt like everything I once knew had. I was, up until this point, what Morrie had called, one of the many people walking around half-asleep. Unhappy, doing things out of routine, that wouldn’t mean much when you were lying on your deathbed. I wanted to do something big with my life, I knew now, it was precious, fragile, and not to be wasted. Dying demanded examination. It put a microscope on your life. With Gavin sick, I

realized a shift in my perspective. I noticed the small change in weather – a drop in two degrees; the crow gradually building its nest in the backyard tree; the wonderful sensation of wind. Death brought focus. It was wonderful yet secretive, like I had discovered a new world. But no one else occupied it but me. The only way I felt connected was by reading the obituaries in the Union Tribune, by trying to learn something from the people who had passed. The world I lived in was not built to support the grieving. There was no space for grief or loss. What Morrie said about this feeling was, “Well, for one thing, the culture we have does not make people feel good about themselves. We’re teaching the wrong things. And you have to be strong enough to say if the culture doesn’t work, don’t buy it. Create your own. Most people can’t do it.”

He was right. The culture didn’t have a place for sisters of the terminally ill. We were in the times of reality TV showcasing glamorous, perfect lives. There needed to be a change in the culture, even if it started within me, my culture, to create a dialogue, a space of acknowledgement and acceptance. It was kind of like the two prayers. There were two ways to go about things: negatively and positively.

And I had a choice.

II.

Today it is raining.

I walk downstairs in my pajamas and realize Christmas is coming and the house isn't decorated. We always set up Christmas the first week of December and it is almost the end of the second week.

I find Mom at the computer, Gavin in her lap. She's started blogging. The site is called, HelpBabyGavin.com. She started it the day after the Benefit as a way of thanking everyone and keeping people in the know of Gavin's life. I haven't yet been able to look at the site. It is a virtual diary for Mom: a platform for her to reveal the truths of our life with Bubba. I plop down on the couch facing her with her back facing me, typing on the computer. I listen to the keys pattering awkwardly. She takes a break every now and then to touch her chin, crawling her fingers across her skin, looking for little chin hairs to pick at. She does this when she is thinking, bored, or nervous. Usually nervous, though. Mom sleeps 4-5 hours each night. Gavin wakes up six times per night on average. The bags beneath her eyes have darkened. Her voice has quieted. I scoop the newspaper from the counter, and move to the couch, fiddling with my hair, searching for split ends.

"Hi Mommy," I say. I flip through the obituaries in the newspaper, studying them.

She says hi, asks about my night, I say it was okay, she says that is good.

I don't think Mom knows how I feel: just like the weather outside – dark, putrid, unforgiving. Telling her would add to her grief. Instead I ask her how Gavin is.

"Gavin is having a little flare of the jumpies," she says. It's as if someone is hiding behind a door and jumps out and scares him. Kind of like vertigo.

I nod. What can I say? What can I ever say?

“We heard from Dr. Crow this morning,” she says. “Gavin’s spinal fluid results tested positive for atypical AGS.”

I ask what that means. I get up and stand next to her. She shows me an excerpt that Dr. Crow has written in the American Journal of Genetics. She says the next step is a blood sample that they will send over ice to England once January comes. With atypical AGS, there is a chance that the 2b subtype, which Dr. Crow suspects Gavin of having, has a much more optimistic outcome.

“If it turns out Dr. Crow is right, Gavin will have some cognitive function and language,” she says and points to the journal, underlining a sentence with her middle finger, something her and Grandpa both do. “Only eight percent pass early on versus eighty percent of the other types. This is something to hold onto for now.”

For the first time in a long time, I feel my eyes fill with warm water. Mom’s eyes mirror my own. We both look down to Gavin lying in her lap: eyes closed, shoulders tense, arms crossed. *Something to hold onto.*

Later that morning, something happened to Mom. I exited the bathroom after my shower and she was folding laundry by the couch. She turned, with full cheeks, and asked, “Are you ready to go to the Christmas show?”

I’d either completely forgotten or she hadn’t invited me until now. All that was on my mind was getting away. Early afternoon I was to board a plane and head to San Francisco to visit my childhood friend Ellen, Kathleen’s daughter. Mom was taking me to

the airport. She also bought my ticket; her way of giving me what she couldn't. I knew she wanted to get out of this house just as I had.

“I don't know if I have time,” I said.

“Of course you do,” she said. “Come on, I'll help you pack.” She said this in a stronger tone, the voice of my mother I knew before the diagnosis.

She sat with Gavin on my bed. After lying him on his stomach, she laid sideways next to him, propping her head up with her hand.

“I wish you could come,” I said.

“Me too, honey. But Gavin is too fragile to fly and I can't leave him with your dad,” she responded.

She then asked me to watch Gavin while she showered. I said, yes, as I changed into a pair of black leggings and a red sweater with black boots that went up just past my calf. Gavin, still calm, looked curiously at me and around the bedroom. I sat next to him, patted his bottom. “What are you going to wear, handsome?”

This was my first Stein Christmas show, a performance put on by the school she was an Occupational Therapist at, when she still worked. The students here were special needs – ranging from very low to high cognitive, social abilities. Mom, Danika, Sydney, and I walked from the parking lot, past the playground. A couple of boys were riding their tricycles in a circle around the grey asphalt.

“Hi Jerry, hi Bobby!” Mom shouted towards them. They kept riding their bicycles, but both shouted out in unison, “Hi Kim!”

I was amazed they remembered her. She hadn't worked here – in what – years? She'd quit being an OT to focus on practicing medicine. At one time she worked both jobs. Now had no time to work any.

“I miss working here with these kids,” she said, turning back to Danika and I walking behind her and Sydney. We'd picked my sisters up from school. “We're pulling them out and playing hooky today,” Mom said to Dad earlier in the morning while he ate his bowl of cereal. “As long as they don't have any tests today or early next week,” he allowed.

We took a seat in metal folding chairs near the front row. Gavin had on a white sweater with a sewn Christmas wreath. Mom wore a red sweater with a Christmas tree pinned over her left breast. The show began with a few Knock Knock jokes by the two MC's – one a speech therapist, the other her student.

“Knock knock.”

“Whose there?”

“Snow.”

“Snow who?”

“There's snow business like show business!” the student shouted, joyfully with a slur in his speech.

Each class performed (or tried) a dance to a song. I watched them move across the stage – not like a ballerina would – but out of unison, uncoordinated. They were older, higher functioning versions of Gavin. Most of the kids could walk and had accurate range and control of their limbs – but many had slurred speech, poor eye focus, and often

lacked control of their mouths. The lowest functioning were strapped to their wheel chairs. I took a sip of my coffee, taking in the moment. Although these humans, these children, were imperfect, they were alive. More importantly, they were loved. What I had failed to notice, before the end of the show, was that the room was packed to capacity with family members and friends of the performers. For a ghastly second I felt a rush of hope, that if my brother made it to this stage (and I prayed, now, he would) he too, would be alive. But that gasp of hope diminished as the show ended, and the curtains closed. Grief moved through me, with the pain of knowing my brother may not even get here, to this stage. The lights dimmed. A slideshow of the students throughout the year played to Billy Joel's, *Vienna*. Mom turned to me, crying. "It's too bad," she said, and then looked down into Gavin's eyes continued, "He's so cute."

That evening I arrived in San Francisco. Ellen picked me up, asked if I was hungry, and we headed to Denny's. We ordered fried chicken strips with over-sized dipping bowls of ranch dressing, fries, and of course, I ordered a salad with low-fat dressing to cancel all the bad stuff out. I'd ended my veganism stint a couple weeks ago when I was walking aimlessly around the mall one day, hungry, then ate orange chicken from Panda Express. I couldn't control anything, I thought. So I punished myself by purging. But being with Ellen, a total non-vegan, I didn't mind the fried goodness and creamy ranch married in my mouth.

Ellen had dropped out of high school that year and I had dropped out of college. In a way, we were on the same wavelength. I believed she was grieving a landslide of

things: the loss of her father 7 years ago when she was 11; moving to a new city, from San Diego to Half Moon Bay, a quiet, foggy beach town southwest of San Francisco; and dropping out of high school. But she was excellent at hiding it. She rarely cried. The last time I'd seen Ellen cry was before prom. Since she hadn't gone to her own, I invited her as my date – and no, not in a lesbian way – but a best friend kind of way. I remembered it strikingly. We sat in her white Honda, looking in the mirror at our newly styled hair. Ellen, I remembered, had begun to weep. Tears ran down her face, black mascara followed. I asked her why she was crying. She didn't know. "Sometimes," she said, "I just need to cry." Then we burst into laughter, and I wept with her.

After Denny's we drove through the winding roads to Ellen's home. Half Moon Bay was a cold, isolated town. I'd imagine a scary movie could be filmed there. The town was known for Mavericks, a big surf competition with waves the size of a 2-story home, and it was a popular mating place for Great White Sharks. There was your horror film: two surfers go out the night before the big competition, disappear into the dark sea, a city of Great Whites come in all Sci-Fi (think *Deep Blue Sea*) style and ravage everyone in the competition the next day. My mind was becoming more imaginative, a place for escape. Before coming to San Francisco, I wasn't certain what I wanted out of my trip. Unlike other events, I hadn't overthought this one. I wanted, I guess, a break.

Ellen and I spent the next day driving. We drove all around the city and down Pacific Coast Highway to Santa Cruz, windows down, music high. We slurped up strawberry frozen yogurt, and chowed fresh turkey sandwiches. We sang, we took pictures, we

forgot about the rest of the world. That night, we watched *Coyote Ugly* to fall asleep. When Ellen was asleep I snuck on her laptop. The moon shined its way through the crack in the curtains onto my black nails thumbing the keys. I typed into the search engine: Help Baby Gavin. His site was the first to show up. Mom had posted. I turned away, thinking, why torture myself. But I had to know. There was urgency. Gavin was almost 6 months old. That meant if the doctors were right almost half his life was over.

12/14

Friday:

Yesterday was a good day for Gavin, several in a row. We were able to attend the Stein Education Center Holiday Show (The special education school where I have worked as occupational therapist) We saw many friends and kids.. The show was great. Then we took Gavin's big sister to airport, and had uneventful car ride. A FIRST :)

TODAY..however, the Monster has returned. Gavin is jumping/startling and irritable. These days are very hard for all of us..I call it Neuro-genic colic. We hold him most of the day, and keep him medicated. I cry and pray he will smile and know me/us when the spell is over and the monster goes away. Please pray for him too, that he will be comfortable quickly, and he will not lose any skills, and continue to recognize us. He was doing so well visually and socially this week, looking at books, himself in the mirror, new vocalizations, and sitting in Sam's lap up to 20 minutes contented. We hope to return to that level.

Hospice RN and chaplain here today..Gavin holding at 16 pounds, despite his dislike of Soy formula. he is on 2/3 breast milk (pumped he has yet to successfully nurse

again) and 1/3 similac.

Will update you all soon, Kim

I closed the laptop and turned over with my face into the pillow, closed my eyes, and breathed into the gray fabric. Pools formed into the sham.

That morning I woke to the smell of crisp bacon, buttery pancakes, and chatter coming from downstairs. When I arrived in the kitchen, Kathleen and Ellen were sipping coffee in their pajamas.

“Good morning, Courtney,” Kathleen said. “Coffee?”

“I’d love some, thank you,” I said.

Kathleen was someone I trusted. She hadn’t turned her head, like some of Mom’s other “close” friends had at the onset of Gavin’s prognosis. She and Mom met as sophomores in college at Western Michigan. They were in a diving class together. One cold morning, Kathleen hovered at the top of the high dive, afraid to jump. Mom, from down below, shouted, “Just do it!” Kathleen eventually jumped but never showed up to the class again. But somehow that moment connected them forever.

The sun lit up the kitchen. Kathleen handed me a warm cup and I sat down at the table. The last time I’d been here was a couple weeks after Gavin was born. Before he was sick. He was so tiny, just over the size of a football. He had new baby tan skin and little hair sprouted from the top of his head like a carrot. Mom glowed with excitement to show him off to Kathleen and her family. I couldn’t remember if he’d started showing

signs of being ill yet. I could only remember through the pictures. I was wearing a red sweat suit with a black shirt on underneath.

Between bites of juicy bacon breakfast sandwiches and sips of coffee Kathleen, began to tell us about her recent trip to Oahu, Hawaii. She had visited her friends Susanne and Bill. Bill had been sick with cancer, and she had wanted to be with Susanne because ten years ago she lost someone to cancer, her husband, Marlo. During Kathleen's visit they shared stories.

“Well, you know I'm a little squeamish about these things, but while I was in Hawaii, Susanne and I exchanged some stories, and one really stuck with me. It was about an outer body experience Susanne had.”

She took a bite of her sandwich, and wiped the crumbs from her mouth.

“I'm not really a spiritual person,” Kathleen said, “But I listened anyway.”

One night Susanne put Bill to bed downstairs in his medical bed. He asked her to stay with him, but she said, no, she was tired. Within five minutes of falling asleep she felt something nudging her, telling her to get up. She'd open her eyes and it would stop. Then five minutes later it happened again. Then again. When fifteen minutes had passed, which felt like hours, Susanne felt like she was punched into a wall, and saw this bright blue in the room. The next morning, she woke up, unknowingly, next to Bill, who would pass later that day. When he opened his eyes she saw the same blue she'd seen the night before. Concerned, she told many of her friends. They referred her to the town's psychic, a small Vietnamese woman. It took her two months to get an appointment. During her visit, the woman shocked Susanne. She was correct from predicting the meaning of the

tattoo on her leg, to her past and to the future, and about Bill. I believed in the gray area. The stage between life and death, heaven and earth.

“When Marlo died,” Kathleen said. “Out of instinct I slept on the couch next to his bed in the downstairs bedroom. His voice woke me the next morning by saying, ‘It’s time for me to go.’”

“I couldn’t believe it,” she continued, “He repeated himself. And said he had been so tired. He said today was the day he would leave.”

Marlo passed a couple hours later, the day before Ellen’s eleventh birthday, allowing enough time for final goodbyes.

Kathleen’s story tingled the hairs on my arm. I shuddered, turned to Ellen, whose brown eyes watered, staring at her mother.

“That’s an amazing story,” I said. “I believe it.”

That night Ellen and I escaped the city for the snow. We packed our bags, borrowed snow gear from her neighbors, and spent the day in Tahoe snowboarding. During the trip I thought a lot about what Kathleen had shared. She didn’t talk much about Marlo, but I didn’t ask. I should have asked more. I should have talked to Ellen about losing her father, how it made her feel, how it affected her. I should have asked Dad more about his mom. I should’ve asked about his favorite memories of her, how she wore her hair. I should have asked Mom more about her mom. What she did for work, what she believed in. But I didn’t. I was a coward in the face of death. I didn’t ask because I was afraid it

was insensitive to ask, intrusive. I was so wrong. If Gavin died I'd want people to know his story, his love, his life. In order to keep the dead alive we needed to talk about them.

III.

Back at home I couldn't sleep. I tiptoed downstairs around midnight after tossing and turning for hours. I grabbed an apple, a few pretzels, and a glass of water and entered the television room. Upon walking into the room, I noticed Dad passed out in the recliner, mouth open, quietly snoring. Most nights I found him here. I quietly slipped the clicker from his grip and flipped through the late night channels. I watched a few episodes of *The Hills* on MTV, a reality show about early twentysomethings whose lives seemed embarrassingly easy. All they did was go to parties, shop, go on dates, and then create drama around their little world. After that bored me, I flipped the channel. This woman with big white hair caught my attention. Her name was Suze Orman.

I studied her. I had never heard of her before. She seemed rigid-like, but strong. Her eyes beaded right at me as she preached about why women needed to be in power of their money. And that it was important to never give up their power. I watched her, thinking, Okay lady, unless you are going to single-handedly teach every woman how to be their own personal broker, then you are wasting your time. I kept watching and learned she planned on doing just that. At two in the morning YOU could break out your visa and dial the 1-800 number, which would lead you to an associate of hers and purchase her DVDs on everything you needed to know.

I mean, I was not going to buy her DVDs at two in the morning, but her story moved me. Suze Orman didn't always have it all. She was homeless in her early twenties and chose to live out of a van for three months until she landed a job as a waitress at a little shop in Berkeley. She spent some years there. Near the age of thirty she realized she

wanted to open up her own restaurant. The trick, though, was that she needed 20,000 dollars to do it. Her parents had no way of lending her the money. One day she told her dream to a regular customer named Fred. His friends and he handed her a handful of rolled up checks, with a note telling her she could pay him back later, if she could. She was given 50,000 dollars in an instant. He told her to take her money to Merrill Lynch right away and invest the large sum. She did, or at least she thought she did. A sharp looking man in a pin-striped suit told her to sign a document if she wanted to earn an extra 100 dollars a month with her investment. Without putting too much thought into the seemingly great offer, she signed. Next thing she knew she was out fifty grand, with no way of paying back Fred. The nicely suited man scammed her out of all her money. She had no idea what to do. Then it came to her: she needed to learn to be a broker so she could make money off of other people's money. She acquired a job at Merrill Lynch, and before she knew it, she sued them for all of her money back. She got all her money back, plus interest, and a whole lot of power and knowledge.

She sent Fred 50,000 back and she found out a couple years later that the money saved his life, literally. He needed it to help pay for treatments for a horrible sickness he had developed. Her resilience, her fight, moved me.

Not everyone could relive Suze Orman's story, but they could take away important lessons and apply them to their own lives. That stupid saying rang in my ear, the saying that near haunted me, *Everything happens for a reason*.

What looked bright was that my painful circumstances might one day come to an end. Resilience could help keep hope alive.

IV.

I'm in the other living room, the one that outlooks the front street and Mom's small flower garden. It's five days before Christmas and I begin to decorate the tree. We finally drove down the road to the local pinery late last night. I waited until this morning to dress it, so the fresh branches could fall in a triangular silhouette. In my hand I hold a rusted cradle – an ornament – my godmother, Cheryl, gave me. Before I could talk, before I could remember. My sisters have one, too. It is the one ornament we make sure to hang up each Christmas ourselves. The cradle is silver, about the size of my fist, with my name and birthdate etched into the side – an empty cot, with a red bow glued on top. But years have passed, and mine is covered with an old film. I lick my fingers; try to smudge away the grease to uncover my name. No luck. Though it is mine. It signifies my first Christmas, and the gift of its soot represents the Christmases it has survived. The years I have been alive.

I dangle it on a pine branch, next to a framed pastel ornament of me at three – dressed in a snowsuit and white beanie covered in hearts. I stand no higher than the countertop, smiling, holding training skis. The image evokes a fear in me. I fear Gavin will receive the same cradle ornament this Christmas. The red bow, still perfectly glued on. I fear this same ornament will haunt me – as each new Christmas comes. That it will age alone – without him.

Anxiety prickles me. I have let my mind go to the dark place. To slow my heart rate, I sit down. I think of God. When something like this happens how can one not

question God? I'm simply supposed to believe that *God sends such tests and afflictions only to people He knows are capable of handling them, so that they and others can learn the extent of their spiritual strength.* Because in this moment, I feel stranded in the middle of a ravish sea, with no one but myself.

There are the facts: Gavin is dying. And there is another fact – more of a question for God – when my brother passes, how can I live? How can I continue to breath? To drive in a car without looking to the middle seat, the empty car seat – to not choke myself with the abandoned baby blankets. When we think about mortality we think about our siblings, children. Is there a pain too great to withstand on this earth? Or if I do trust in you, will I find some strength, even when I feel hopeless? There are so many questions, and the answers feel infinitely far. And there may never be answers, I understand. I have met people who can tune things out better – it is as if they make themselves forget. But everything in this life is a constant reminder. I want to scream from my bedroom out of the second story. To reel on the roof of this house, kicking and cursing the sky, and not care if I fall off. That is the pain. The pain that can never go away.

I understand the people who have taken their lives. Each day I understand more. But how can I be stronger than them, in the defining moments that bring us to our knees?

The deeper fact is that I love God. I trust Him. But I am scared no one will be there to pick me up when I fall. Because the ones I love have also fallen.

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The color black is the darkest color, and is the result of the absence or absorption of light. It is the color an infant absorbs in the womb, and according to Christian theology, the

color of the world before God created light. It seems that we have all fundamentally come from darkness to light. And it also seems we are not free from it, just by living in light.

I wore a lot of black that winter. Mom worried about why I wanted black nail polish for Christmas, even though my nails were already painted black. I also wished Jake, my manager, would kiss me. And wondered if Tariq, my co-worker, knew that his phone calls saved my life.

The following morning, after decorating our own tree, I arrived early at work to decorate Rockin' Baja's Christmas tree. I enjoyed working mornings. It was my little Sunday morning escape where I often imagined myself to be someone else. Jake, the assistant manager, worked the morning shifts, and most times we would open the restaurant together. Earlier this morning, I was feeling especially vulnerable and confident, so I brought him breakfast from the bagel shop next door. I also wrote him a card. I didn't realize how horrible this was of a choice until it had already been done.

Jake was probably a decade older with light brown hair, fair skin, blue eyes, and black-framed glasses. He was into photography and was always nice – he noticed when I had cut my hair or when I was in a Mood. I was obscurely infatuated with him. He was a Cool Dork. But from a distance. To my knowledge he was single. When it was just the two of us I imagined myself going up into his office that you had to climb a ladder to get to, gently sit on his lap, and kiss him. Fiercely. This obviously never happened. But thinking about it made pleased me. There were rumors around the restaurant that he had a crush on me. He liked to stand next to me at the host stand and chat the entire night. Other servers said this made the other assistant manager, Liz, mad, maybe jealous.

My card detailed how awesome I thought he was and told him he should quit the restaurant life and go after his dream as a professional photographer. After I gave it to him he said, thank you. Then later, when Abby came in, she told me Jake and Liz had started dating. They had been dating for a while – maybe a couple weeks and now they were official. I stopped talking to Jake and slowly watched him and Liz flirt more at work. There was no one else for me, I thought.

Vaguely heartbroken, a couple of days later, I agreed to go with Tariq, my co-worker who I talked with on the phone about Life and Gavin, to Yardhouse a pub a few blocks north of Rockin' Baja. We had never hung out outside of work besides the time we met at Starbuck's, before we were hired at the same restaurant without knowing it. Tonight, he had wanted to take me out and I had Kelly's older sister's ID.

We sat across the booth from each other. Yard long beers sat on the table in front of us. Smells of fried onion rings and crisp pale ales cluttered the air. Some of his friends were there; he introduced me to all of them. I felt like he was proud to have me there. When the night was over it was raining outside and he said he wanted to walk me to my car. On our walk through the rain, about a block from my car, he stopped me on the corner of 5th and J Street. He grabbed me and turned me to face him. I stood about three inches shorter than him so I had to look up to see what he was doing. He put his hands on my shoulders, then on my cheeks. I took my hand and wiped the rain out my eyes.

I looked up at the cloudy black sky, the beauty of the rain falling onto his masculine face. Tall city buildings and Christmas lights gathered in the background. I looked at the burn mark that ran from his left cheek halfway down his neck. He never

talked about it and I had not a clue how he got it but it didn't bother him. Confidence had concealed it. I didn't touch his face back. Instead I crossed my arms in front of me, and blinked cold rain from my eyes.

"I've been wanting to kiss you," he said. I blushed.

He had told me multiple times he wanted to kiss me, but why would I, that would give him what he wanted. I locked my light eyes with his dark ones. I then closed mine and felt his cold lips whisk up against my own.

After a few seconds, I pulled back. "I've never kissed in the rain," I said, followed by that nervous laugh Dad did. I'd seen actors kiss in the movies. It seemed romantic and fun. And it kind of was. He hugged me, took my hand, and walked me to my car.

"Be safe, kid," he said, and then waved – more like a salute.

Kid. I rolled my eyes and drove away.

V.

With Christmas approaching, Mom takes Gavin to sit on Santa's lap. She tells no one. It is her special, secret moment. She stands behind another woman with a boy around two. The boy jumps on Santa's lap without a helping hand. Smiles. And takes his picture. They leave, happy, without thoughts of Christmases to come. When it's Bubbba's turn she is cheerful – as long as she can. Then the feeling is too much, and the rivers flow down the wrinkles in her face. Age, she says, is a gift. And as Santa listens – his heart grows. It's my son's first Christmas, she says. But it may also his last. She releases the tense air through her nose. *It is never okay, it's always unfair.*

Santa listens, his white glove patting Gavin's head. The woman behind the camera shakes a rattling toy at Gavin. He coos, and the picture comes out perfect, in a Gavin type of perfect. Mom cries and Santa loses a tear from his eye and tells her to put away her money – it's no good here. He takes her hand and holds it. I'll pray for him, Santa says. I will bring his story to my prayer group, and we will pray for him. If that was Mom's only gift, it was enough to know. Santa cared.

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This Christmas Eve I took my sisters and the neighborhood kids to lunch, a movie, and the park so the moms could get their last minute wrapping done. Later in the evening we had a late turkey dinner with Dad's homemade gravy. After, we attended a wonderful Christmas Eve Sermon at a neighborhood church Sydney had been part of a

Christmas play at. When we got home, around midnight, we each opened a present, and Aunt Karylee came over for treats and Champagne. The evening was lovely, at last.

I woke Christmas morning to Danika, wearing her Sponge Bob pajamas, jumping on my bed, “Wake-up, it’s Christmas!” I told her I’d meet her downstairs. Dread, my new friend, was curled up next to me.

When I arrived downstairs, Mom kissed and hugged me and wished me a merry Christmas then abruptly asked, “Honey, can you hold your brother?” She then ran from the kitchen into the bathroom. I poured hot water into my coffee mug, then stirred my hot cocoa I took my time, watching the liquid thicken in my favorite beagle coffee cup. I knew I couldn’t ignore him for long because he was crying, and the longer I waited to pick him up, the louder he’d become.

“Sure.” I looked down at him, lying in his blue egg baby chair. Well it was a cross between lying and sitting. I guess he was resting. He still couldn’t hold his body up, and was not expected to, but Mom had been working with him on holding his head up. Gavin’s face was red, mouth open, and fallen tears pooled in the collar of his shirt. I bent over, gripped my hands under his bony armpits, and lifted him onto my right hip, bouncing rhythmically.

“Gavin, shhh.”

I patted his back.

“Gavin. Shh. Stop crying.”

His cries dissipated. I carried him into the living room. The Christmas tree looked prematurely aged, filled stockings scattered the fireplace, and Silent Night played in the background. I could hear Mom beginning to heave from the downstairs bathroom, and the smell of sausage cooking on the stove filled the room with a smell I couldn't find comforting. I walked over to the fireplace, gently brushed my fingers over Santa's Christmas Eve plate and mug we left out the night before. There were half eaten cookies, and nibbled carrots. Mom and Dad still consumed the majority of the goodies left out for Santa and his reindeer, because Sydney still believed. Next to the ceramic Christmas plate rested a letter addressed to Santa. It wasn't a tradition for us to leave notes for Santa, so I quickly unfolded it, curious.

Dear Santa,

I don't want a lot of presents this year. Well, I want some so I don't feel left out, but I wanted to ask you a question. Do you know any people up there who could help Gavin? He is really sick. He has a disease that only forty people have in the world, and many don't live very long. I can't say the name because it's in French. That is the only thing I want for Christmas. I don't like to see my family always so sad, and was hoping you would know someone who could help. Please!

Sincerely,

Sydney

P.S. I am writing this really fast so sorry if its messy, but I don't want my mom to see it because it would make her cry.

I set the letter down and took a seat on the Navajo couch, Gavin still in my arms. I reflected upon my urge to cry.

I was mad at myself because I always cried on Christmas, usually over ridiculous things, like not receiving the right outfit or gift from Mom. Even this past week Mom had come home from shopping at GTM, a local discount store, with a brown and black jacket with images of shadowy horses on it.

“I got one for each of us. Aren’t they cute?” Mom asked.

I gave her The Look. The awful look I was accused of giving whenever I wasn’t satisfied. She had noticed, like always.

“I can return it,” she said. “You can pick something you want.”

I told her no, I’d wear it. I wanted Mom to get my fashion sense, but she wouldn’t. Her face torched red, embarrassed by my disapproval. This was the quality I deeply hated about myself. Like really hated. On the level, that you could think I was a bad person, and I couldn’t argue a case against you. There were people, like Dad, who were good at acting or faking or whatever you called it. They appeared genuinely grateful, even if they weren’t. I was an awful liar, an awful faker. This was my dire curse. Why couldn’t I just be happy, satisfied over the thought?

If things weren’t perfect, I cried. I was beginning to think I had a problem like acute holiday depression. The only Christmas I hadn’t cried on was when I received my dream gift, Sasha. That special Christmas morning I walked downstairs and heard a small

whimper coming from near the front door. A beautiful purebred beagle, with glitzy green eyes and a red bow around her neck was mine.

Five Christmas' had passed since I got Sasha, and I cried during each, for a variety of absurd reasons. Usually they had to do with change or disappointment. Once, I cried silently because my cousin no longer came for Christmas because he was attending Law school, and we would no longer be able to play Risk, a board game of world domination. I also cried one year when Dad changed the menu for Christmas dinner from turkey to ham. Then there was the time my parents were poor and the gifts to Danika, Sydney, and me weren't evenly distributed.

“But you got Sydney ten gifts.”

“And Danika nine!”

“And me, only three.”

“Well, yours cost me more, honey.”

Over the years I had become Veruca Salt from *Charlie and the Chocolate Factory*. When I thought back to these moments, I cringed.

I cringed because this morning was different. This morning I sat with Gavin alone in the living room we rarely used, except for Christmas and birthday parties, on the Mojave style couch, with my face burning, holding back tears. I was wearing a Santa hat, hoping it would improve my mood. Sydney's letter was a bitter truth no one had discussed prior to today. We all went on with the season the best we could, and today we all would face the pain of reality. Gavin was sick.

I continued to cradle him and coo him, but he remained agitated.

The Christmas ornaments that hung from the tree tormented me. I thought of the gift Gavin would receive later – the baby cradle. Mom confirmed that Cheryl had gifted him one.

I held Gavin close to my chest, kissed his forehead, and felt my soul shake. I wished I could take back everything, all the wasted tears of Christmases past. I would have given up everything for one thing: him. I would trade my life, for him to live his. I began to palpate. Anxiety coursed through me. *This was not my life. This couldn't be my life. This couldn't be his life.*

Dad came running into the room holding his spatula. Danika just stared.

“Is everything alright?” Mom asked, exiting the bathroom.

“No,” I sobbed.

“Here honey,” Mom said in her calm voice. “I’ll take him.” She took Gavin from me and held my head in her hands.

“Don’t worry. Not all Christmases will be this way,” she said.

When she held my head in her hands, I clung to her, my beautiful, strong mother, the woman I wished I could be. I cried into her knit sweater. *A desperate attempt to steal something from Death’s suitcase.*

When Sydney woke up a little later, still dressed in her fleece nightgown, she walked over to the fireplace, looking for her letter to Santa. When she found it, she scooped up the letter, examining it.

“Santa saw it!”

“Saw what?” Mom asked.

“The letter,” Sydney said.

“Let me see, bring it here,” Mom said.

Sydney came over and snuggled her body between us on the couch. Even Dad stopped cooking for a moment to come see. The six of us: Mom, Gavin, Danika, Dad, and I listened to Sydney read Santa’s response written on the back of her letter.

“Dear Sydney, Don’t be sad. Santa knows about Gavin, and is working hard with the angels to make Gavin better. Keep being the great big sister you are. Be good. Love, Santa,” Sydney read.

I glanced at the letter. It was written in Mom’s handwriting.