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KIDNEY TRANSPLANT: MY FAMILY'S JOURNEY

by

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I'm finally in my room, high on the tenth floor of the recovery building. Like a monstrous creation of Dr. Frankenstein, I have a central line in my neck, a tube in my belly, and a tube in a place that I'd rather no doctor ever go near. An antibody called ATG is circulating through my veins. Powerful immunosuppressants are wreaking havoc on my white blood cells. The counter on the IV stand says that I need twenty more minutes. The alarm will sound. One of the nurses will hurry to change the bag and I'll be on fluid for the rest of the night. Fluids in and fluids out. They'll measure it, empty it, measure it, and then I'll be left alone for a few hours.

I've just received a kidney from my older brother. He's somewhere down the hall. The last time I saw him, I was in the bed waiting to go into surgery. The doctors wheeled his bed past mine. A quick high-five, a smile, a "see you when I wake up," and Eric was

whisked away. I wasn't as frightened as I thought I would be. An hour with dad's ancient six-string on the couch before leaving home and I had felt ready. A slightly altered verse from the bible kept echoing through my mind.

“Though I walk through the valley of the shadow of death, I shall fear no evil for I am the baddest mother that walks the land.” To this day I cannot remember how the actual verse ends.

I had been nervous, but not frightened. That is until they wheeled me into that white sterile room, a peripheral IV in my arm pumping god only knows what into my body. They ask me to scoot myself on to the stainless steel table. The less than dignifying hospital gown and thin blanket are little comfort against the cold metal. That's when I felt scared for the first time. Gazing up at blinding lights above as an enormous hand lowers a mask over my face.

“Is it too late to change my mind?” I wonder.

What are the options? Dialysis? I had passed out when the doctors had explained that option. Dialysis had meant no more backpacking, no more rock climbing, no more feeling the icy winter wind on a knife-edge mountain ridge, no more life. There is no other option. My eyelids grow heavy. The lights go out. My journey has begun.

The journey actually began a long time ago. I was nine years-old when I was diagnosed with Retinitis Pigmentosa, a degenerative retinal disease that could one day cause me to be blind. At the age of nine, that had meant little more than “I see the world differently than other people.” There was a study being conducted at the Massachusetts Eye and Ear Infirmary to determine whether Vitamin-A could be used to slow the loss of

vision. Before I knew it, I had I was taking a single monstrous pill every morning. A “simple” blood test was required every three months to check for side effects. When you’re nine years-old, no test that involves a needle is “simple.” Within a year, the blood tests revealed that my Vitamin-A level had soared far beyond normal. I was immediately taken off the medication, but the blood tests continued. There was hope that if my levels returned to normal, I could rejoin the study. My levels never did return to normal.

In eighth grade, I had yet another routine blood test. I walked from school at the end of the day to the local health clinic where my mother worked. She entered the order into her computer and I went through the all too familiar routine of clenching a fist and waiting for the sting of the needle. However, my mother had entered the less expensive full batch of tests that she would normally order, rather than the single test that Boston desired. We received a phone call the following day; something was wrong with my kidney levels. My mother had accidentally started the next leg of our family’s journey.

A day later, I was laying on a table with cold gel on my belly while an ultrasound probed deep into me. The woman operating the machine marked one black spot after another on the map of my kidneys. Confusion and concern hung over the white-walled room like a looming thunderstorm while the ultrasound hummed rhythmically. What were all of these marks? Had we discovered some kind of cancer brewing within my belly? I tried not to think about the movie *Aliens* as I listened to the machine.

That afternoon, we were told that I had a number of benign cysts on both of my kidneys. I wasn’t sure what benign meant, but it seemed to be a relief to my parents. I

was told that I had about fifty percent kidney function; I had renal insufficiency. Over the years, I came to understand that renal insufficiency roughly translates to, “Your kidneys don’t work quite right, but no one knows why.” One of the hospital’s kidney specialists suggested another possible diagnosis; a rare syndrome that involved low vision, low kidney function, and extra fingers or toes. I remember looking at my hands and counting.

“One, two, three, four, thumb.”

The specialist had stared at my snowshoe-sized feet and claimed that there might be an extra bone hidden within their massive depths. The x-ray confirmed what my family had already known. Like my mother and my grandmother, I have gargantuan feet.

When my kidney disease was first discovered, I was told that I might need a kidney transplant someday. My parents and I gave that possibility little thought. If I did ever need a transplant, it would certainly happen when I was in my forties or fifties. I hardly thought about kidney disease as the passing days turned into weeks. It affected me far less than my vision. By the end of high school I was almost legally blind. There had been slight changes in my kidney function too, but it could be managed with minor changes to my diet. In January of 2007, slightly over a decade after my first ultrasound, my blood tests revealed that my kidney function had fallen below twenty five percent. It was time to start thinking about transplant. It was time to start thinking about my options for the future.

My mother immediately volunteered to be my donor. There was no question in her mind. Children are always a partial match with their parents. It seemed to be the best

solution. While mom began a rigorous series of tests, I went on with my life as though nothing was wrong. After all, I didn't feel sick. Had it not been for the blood tests, I wouldn't have even known that anything was wrong. I don't remember being worried. I knew that everything would work out in the end. Either my mother would be the donor, my name would come up on the donor list, or--or I would start dialysis. That word still makes my skin shiver and crawl. For many, dialysis is the only option. It's a welcome escape from the nightmare of kidney failure. For me however, dialysis would never be an acceptable solution.

While mom continued to take one test after another, I went to Minnesota to work as a wilderness guide. I had just graduated from the University of New Hampshire with a degree in outdoor education and was off to explore the world. I was away for nearly four months, leading canoe and kayak trips for people of all ages and all abilities. Other than a single blood test at the University of Minnesota Health Center and trying to adhere to a special diet, I hardly had thought about my kidney disease. However, my journey had already started to affect me.

While watching the sunset over the waters of Kabetogama Lake one evening in late August, my friend and fellow guide, Peter, asked me a question that I'll never forget.

"Hey Pirate," he said. Pirate was what everyone called me. I had chopped off my ponytail before going to work in Minnesota and had felt awkward with nothing upon my neck. Wearing a long bright red bandana had been my solution and it had also earned me a nickname amongst my fellow guides. "What do you love?"

It sounded like a simple question. I answered Peter without pausing to think.
“You mean besides life?”
“If anyone other than you said that, Pirate, I would call bullshit,” Peter laughed.

We sat together for a long time while I explained the philosophy that I had adopted while guiding on the trail. Everything is an opportunity, even the worst trials and obstacles. We would be paddling over fifteen miles the next day with heavily loaded boats, but we were lucky to have that opportunity. We were all lucky to have the chance to see whether or not we could do what seemed daunting or impossible.

Our small group slept out on the rocks that night, our array of sleeping bags like a giant patchwork quilt of blue, grey, and red. I awoke the next morning with a crow inches from my head. He looked down at me and I looked up at him. With a raspy caw, he spread his wings and flew over me. I thought little about that moment until days later when I was flipping through a book about the spiritual symbolism of animal spirits at the Minneapolis Public Library.

crow: Seeing past, present, and future together; look with the innocence of a child; feel with the instinct of a mother; see with the eyes of an elder; working in darkness without fear; carrier of souls from darkness to light.

I wouldn't know it until I went home weeks later, but my mother had failed one of the final tests. The doctors would not allow her to donate a kidney. Mom had failed a glucose tolerance test and there was a chance that she could develop diabetes with only one kidney. The doctors refused to even consider my dad because of his cardiac stent. Our journey had come to a sudden halt. There was talk of dialysis. My stomach felt queasy at even the thought of that option. In the midst of the confusion, Eric suddenly called from his home in California.

“Hey Mike, I just had my blood type tested. We're a match.”

“That's great,” I replied. I felt like an idiot. I didn't know what to say. How do you say thank you to someone who's just offered to donate you their kidney? What words can express such overwhelming emotions. Thank you just didn't seem like enough.

“I'm going to do these other tests and see what happens.”

I still didn't know what to say. “Okay.” My mind drifts momentarily back to the crow that I had awoken to on Kabetogama Lake. Had it been a sign of something good approaching on the horizon?

The days slowly trickled past while we waited for the test results. At last we got the call. Eric and I were a partial match. He checked his busy schedule at work and a date was set. He sent me a package the following week. It was my 25th birthday. Inside the small heavy box was a card.

“At your age, you can't afford spare parts,” the card read.

There was a large can of kidney beans within the box.

“But I've got a few that you can borrow,” the inside of the card read.

Due to my restricted diet, I couldn't eat Eric's gift. Instead, it went on a shelf beside my fleecy stuffed animal crow. The darkness of disappointment had turned into the light of hope. We had a plan, and the journey could now continue.

October passed like a swirling breeze of autumn leaves. The big day was lumbering closer and closer. Two days before our surgery, Eric and I went for a hike up North Moat Mountain. For nine miles we slogged through mud and crunched across ice. We returned home that night tired, filthy, and smiling. Was this a taste of what was to come? Every challenge is an opportunity, even the worst trials and obstacles. I had the opportunity to go on a life changing journey. I also had the opportunity to have a family who would go on that journey too.

I awoke from surgery in the recovery room. I don't remember much about the recovery room. There's a thing in my neck, the central line. I can feel tubes against my skin and quietly hope that they aren't connected to me. The nurse drawing my blood from one of the central line's colorful ports smiles at me. There's a thing in my arm. It's called a peripheral IV, but it's a thing; another tube providing access to my innards. I answer her questions with a smile. I hear myself speaking in a cheerful tone as though there's no place I'd rather be than right here. The truth is that I can think of almost a million places I'd rather be, but most people who are sick or in pain forget about everyone else. Doctors and nurses deal with a lot of anger, frustration, fear, and despair. I had resolved long before my surgery day I'd try to always smile and always say thank you. I would be the silver lining to their hectic day of tending countless patients. Another nurse enters my

dominion of blue curtains and beeping machines. She's young, my age, blonde, and she has a charming smile. Perhaps there is a silver lining to every dark cloud.

I remember my entire family being there in those first hours. My oldest brother Jeff and his wife Jaime, my mom and dad, even two of my mother's close friends (my other mothers) had been there that day. Eric's girlfriend, Kristy, is there. Eric's fine, cranky, but alright. I'm laughing. We're telling jokes, making a scene, and probably embarrassing my mother. The world is suddenly moving. The beeping of my machines is getting fainter. I glance around in a momentary panic. No dark tunnel, no bright light ahead; I think I'm good. A room has opened on the transplant floor. We're headed upstairs, headed to the tenth floor.

A nurse guides my bed, another pushes the IV stand and its heavy load of colorful fluid bags. Like an emperor being carried to his palace upon a sedan chair, I am wheeled through hallways. The elevator doors close and we rise towards the dark evening skies of Boston. I am brought into my new room and it is time to get settled for the night, as though that's possible in a hospital. There's a code blue next door. I wish I didn't know what that meant, but I was a Wilderness EMT for four years. I know that someone next door is being sped away to the intensive care unit. It is time to get settled for the night. My parents will be returning in the morning. It is Tuesday night. I will be here until Saturday, Friday if I'm lucky. It is time to get settled for the night, time to rest.

It is my firm belief that it is not humanly possible to actually relax or sleep while staying at a hospital. Those who say otherwise are either mutants or have completely abandoned their sense of reason. I became accustomed to this fact during my first night on the tenth floor. I also learned that it is even less possible for someone like me to sleep in a hospital--someone who can hear a mouse fart from a hundred yards away. The hospital is a menagerie of nocturnal noises; patients coughing, papers rustling at the nurse's station, a siren ten stories below, the IV alarm. My fluids need changing again. The alarm will wail until the nurse arrives. A new bag will be hung on the stand, my urine bag will be emptied and measured. She'll want to check my temperature; it will be low again. I'll then have a few meager hours of what could be called peace. Not tonight though. A dazzling blue light flashes in the hallway accompanied by a siren. A woman's calm and reassuring voice sings out in a cheerful tone.

"A fire has been reported in the building; please proceed to the nearest exit in a calm and orderly fashion."

"Seriously?" I hear myself groan. Sitting up in bed, I momentarily consider the calm fashion in which I would descend the stairs--with an IV stand and urine bag in tow. It's a ten story descent through the concrete tree tops to the pavement below. I lie back and get comfortable. At least I'll die with good kidney function. It's Tuesday night, and I will be here until Saturday.

Morning comes much earlier than I would like. I am greeted by the director of the floor and her gaggle of ducklings. Many of the beaming faces seem to still be growing into their white lab coats and blue lobbed stethoscopes. They watch her with wide eyes

and attentive ears as she examines my belly. She adjusts the adhesive bandage. I hear it, feel it, and know that there is nothing I can do to stop it. I bite my tongue as she rips the bandage away. The ducklings lean closer while their mother fiddles with the tube protruding from my belly. A layer of slimy goop has hardened around my incision, fluids that escaped from within me overnight. The human body is truly a vile thing. I hear the doctor mutter something about the incision looking good.

What planet are you on woman, it's covered in goo?!

The floor director and her ducklings leave to inspect the next patient. I manage to hold back a heartfelt “quack” as they depart. It's now time for the 6:00 a.m. drugs and blood. I swallow the colorful tablets, struggling to remember names, shapes, and dosages. The nurse attaches a vial to the thing in my neck and it slowly fills with thick red liquid. I suppose I can let her have a little. The record before surgery was twenty vials. Today, she only demands four. She tells me that my creatinine level is down to 1.7. That's good, lower than it's been in over twelve years. My kidney function is almost normal. The nurses ask me what I want for breakfast. I'm not accustomed to options. For the past few months I've been on a restricted diet to keep my kidneys happy. Rice Krispies have been my breakfast every morning. Snap, Crackle, Pop, and I have become good friends. Keeping to a diet of low protein and low potassium has left little more than rice and vegetables for my meals. The list of options is too small for me to read. Rather than explaining that I'm legally blind and can't read the list, I point at the middle of the page with a smile.

“I'll have this.”

I hear her mumble something about oatmeal as she takes the list and circles my desire. Oatmeal! Dear God! What have I done?! I add the rough location of oatmeal on the breakfast options to my list of things to remember, filing it under “A” for “Avoid at all costs.” It could be worse though. There’s been a mistake with Eric’s chart. It claims that he needs assistance eating. While the nurses hurry about their morning rounds, Eric’s breakfast sits unguarded and ignored, growing colder with every passing minute. He later complains that someone ate his sausage.

Eric comes to visit after breakfast. He, my oldest brother Jeff, and I sit around the hospital room’s small table playing cards as though we’re gathered at the local pub after work. My IV stand is at my side, faithfully pumping its contents into my veins. Fluids pour in, and fluids pour out. I hope that I’ll remember how to pee when this is all over. A nurse enters the room, smiling like a bar waitress as she delivers a pink plastic pitcher of water. We ask for beer, but our request is met by a disapproving smile. I can almost hear Queen Victoria’s voice in the nurse’s laugh. “We are not amused.”

Tired of cards, I go for another walk. My mother insists on checking the tube in my belly before I leave the room. A small eddy has formed in the clear plastic’s trickling stream of ooze and fluid. A thick glob of tissue is stuck, lying limply across the opening of the tube. Terrified that pressure might build within my tender belly, my mother, the ever-worried nurse, begins to “milk” the flexible plastic. She tugs. She squeezes. She shakes and pulls.

“Mom! That’s attached!”

Finally, the dam of dead tissue tumbles away, and the stream continues its slow trickling pace. I pray that the doctor will remove my tubes before I go home. Gripping the cold metal of my IV stand, I step towards the hallway. Walking past the nurse's station, my urine bag in one hand and the IV stand at my side, I turn the corner and begin the tenth floor loop. The hospital hallway with its bright ceiling lights hardly compares to the crisp autumn sun and muddy trail of North Moat Mountain. My parents and my aunt had bought me books on tape for the hospital stay: *Prairie Home Companion*, *Into The Wild*, and other titles. The truth was that I'd rather be out walking with my feet than reading with my ears. Even the concrete forest and overcast skies of Boston would be better than the drab walls, sterile smells, and beeping machines of the tenth floor.

I pass an open door and see a doctor in his white coat standing by a patient's bed. There are other people gathered around the moaning woman's blanket-covered form as well. I keep walking, but my mind remains behind, listening to the doctor's voice.

“You just need to find the energy to get out of bed today.”

The woman moans in a weary voice.

My mind drifts back to last night; the neighbor being whisked away to intensive care, my roommate lying alone with no one to keep him company. And then my mind drifts back further to that September day--the day that Eric called. Why had we been a match? Why was I so lucky? Why was I walking the day after surgery while others were too weak or miserable to rise from bed? I had a brother willing to take this journey with me, but not everyone is that lucky. I thought about the tens of thousands with their names on organ lists, waiting, hoping.

Time blurred into a daily routine of medical school ducklings, meals, and meandering walks through the hospital's brightly lit hallways. The nocturnal noises of the tenth floor filled my ears every night while I struggled to sleep. Suddenly it was Friday. I would be going home tomorrow. Another doctor comes into my room after breakfast. He is one more unfamiliar face with a white lab coat. The trickling stream of attending doctors, nurses, and orderlies has grown to a raging sea. My dad and I both greet the newest stranger with welcoming smiles.

"Mr. Lang," he says. I can't place his accent. Maybe he's Russian, or maybe he's from an obscure corner of Europe. "How are you today?"

"I'm doing great!" The central line and catheter had both been removed the previous day. The world is a beautiful place. Other than the tube in my belly, I feel human.

He carefully inspects my incision, checking for any signs of infection or other complications. "What did you do before your surgery," he asks.

"I was a wilderness guide," I explain. "I climb mountains and lead canoe trips."

"I knew you were a climber!" he exclaims. "What do you climb?"

"Difficulty? I climb 5.9 and 10, but I lead 5.7."

"I climb 5.9 too," he replies with a grin. "You should come out to Utah. Best climbing in the world! I'll show you around the canyons!"

He finishes his examination and says good-bye. After he leaves, my dad gives me a look of disbelief. "How could he have known that you were a climber?"

I smile in response and silently wonder how many transplant recipients go rock climbing with their doctors after surgery. I would probably be one of the few. The stereotypical climber is not exactly medical school material. For a brief moment, I try to imagine the clean-cut professional clinging to the crux of a 5.9 with his soft surgeon hands. The image makes me laugh. Climbing and medical school are an unlikely pair to say the least.

While I lay in bed that night, I found myself thinking about a story that I heard as a child. A story about an old man walking a beach. Thousands of starfish adrift in the sand, stranded by a terrible storm. The old man stops as he walks, plucking the helpless starfish from the sand, and flinging them back to the water. A younger man comes upon the old man and watches him in disbelief.

“What do you think you’re doing old man,” he demands. “You can’t possibly save them all. What does it matter?”

The old man simply smiles and looks at the little starfish in his hands.

“It matters to this one.”

Far below in the depths of the city, car horns shout and sirens scream. A little starfish on the tenth floor of the Beth Israel Deaconess Medical Center closes his eyes for the night. He’ll be flung back to the safety of the sea tomorrow; back to his family, back to his home. Another night creeps past. I’ve almost become accustomed to the nocturnal noises of the tenth floor. I find that to be frightening. Saturday finally dawns and I begin the long painful wait for my discharge papers. The clock hands move as though they’re

made of cold molasses. It seems like I might never leave the tenth floor. At last the doctors are satisfied. I sign my name and am free to go.

I came home from the hospital a week before Thanksgiving. That holiday means a lot more to me now than it ever did in the past. It's more than just pilgrims and natives learning to be friends and more than grandma's apple pie. It's the opportunity for me to say thank you to my family. Eric and I were the stars of the show, but everyone else came on this journey too. I can't imagine what it must be like for those who face kidney disease alone. I can't imagine what it's like to be on dialysis. Those are two opportunities I hope never to have as my journey continues.

It's been over two years since that November and I still have not found a way to truly say thank you to Eric and the rest of my family. What do you say to someone who's given you a kidney? What do you say to someone who's traveled far to be with you during a difficult moment? Thanks to a generous brother and a skilled surgeon, my life has returned to normal. A scar on my belly and a handful of pills, morning and night, are my keepsakes from this adventure; as well as an unopened can of kidney beans that sits beside a crow on my bookshelf. I still don't know how to say thank you and I doubt that I will ever find the words. Thanks will never be enough.