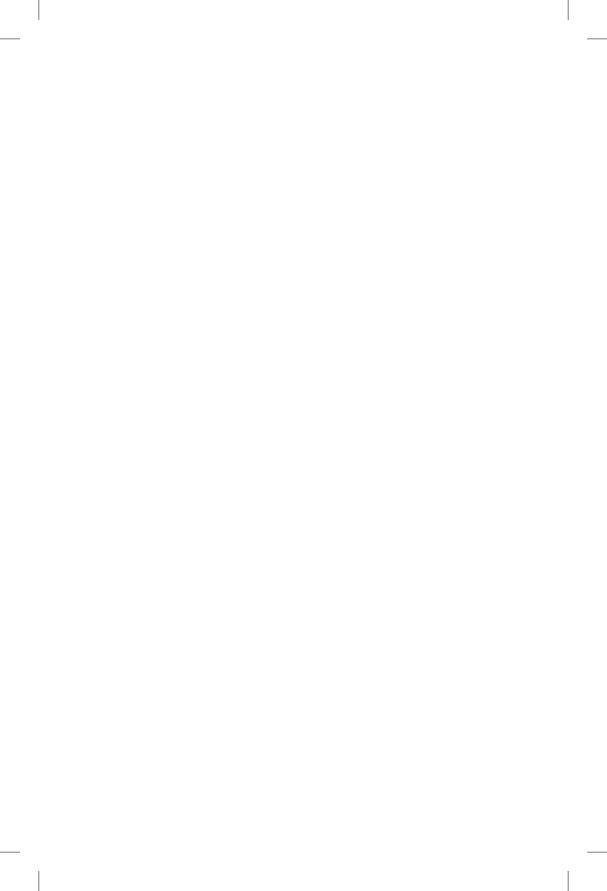
Lifequake



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A Story of Hope and Humanity

A Memoir by
Tarini Mohan



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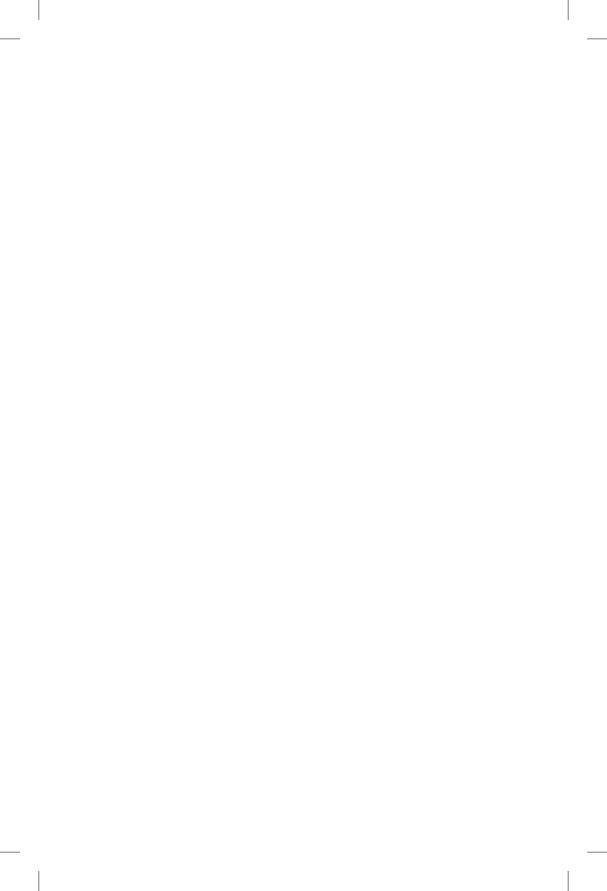
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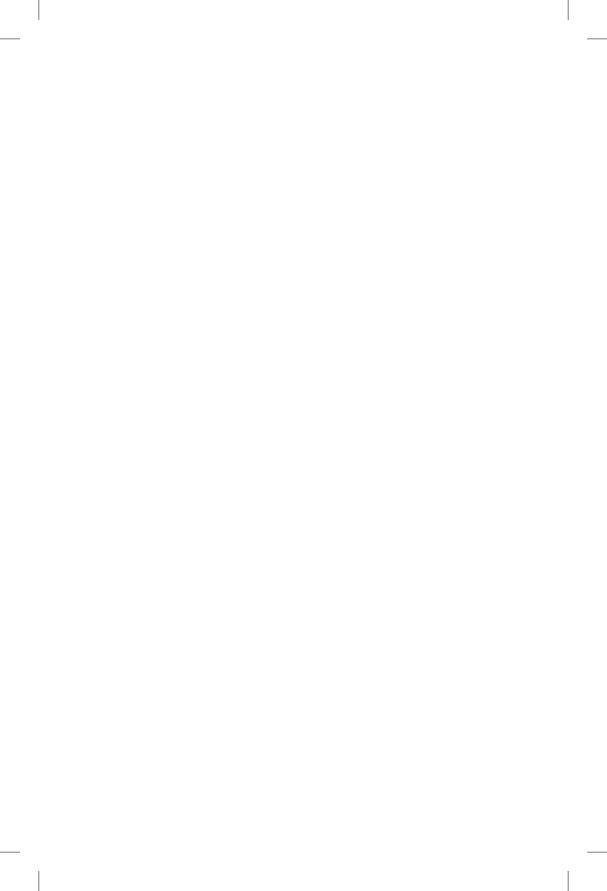
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To my family, whose unconditional love makes living a pleasure

(and a possibility) once more.

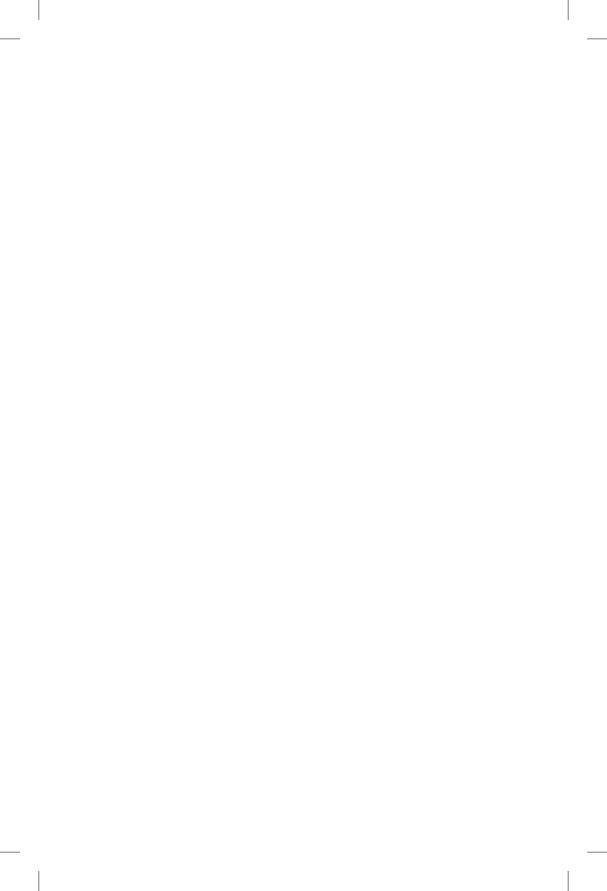


- "I know it sounds absurd, please tell me who I am."
- "The Logical Song" by SUPERTRAMP
- "A bend in the road is not the end of the road ... Unless you fail to make the turn."
- HELEN KELLER
- "We walk the same path, but got on different shoes, Live in the same building, but we got different views."
- "Right Above It" by DRAKE and LIL WAYNE
- "The doors of the deformed man are always locked, and the key is on the outside ... He may have treasures of charm inside, but they will never be revealed unless the person outside cooperates with him in unlocking the door."
- RANDOLPH BOURNE



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Prologue

The wind whipped through my hair as I dug my feet firmly into the footrests on the sides of the motorcycle taxi, ensuring that I was tethered in place. Now, I could spread my arms wide to really revel in the thrill of my newfound freedom. I tilted my head back, enjoying the breeze. It was October 8, 2010, and at twenty-three, I had never felt freer. Six weeks earlier, I'd traded the sleek glass towers of New York City for the vibrant chaos of Kampala, the capital of Uganda. It was a leap of faith, a wild adventure, and in that moment, I was soaring.

Sandwiched between my new friend, Sujal, and the driver of the motorcycle taxi, I felt the wind in my hair as we cruised down Yusuf Lule Road.

Then, in a heartbeat, everything changed.

Screeching tires. Blaring horns. Shattering glass. The sickening thud of three bodies hitting the ground. I drifted into a chasm of oblivion. Time froze. And just like that, three months of my life dissolved into nothingness.

I woke up in India, my consciousness piecing together fragments of my surroundings in snatches. Mumbling some gibberish here, uttering half-formed curses there, I was lost in a sea of confusion and consumed by profound discomfort. My short-term memories slipped away like wisps of smoke. Once sharp and agile, my mind now moved at a sluggish pace. Emerging from another realm, I

confronted the jagged contours of my new reality. With my body and brain altered, I found myself dwelling in an unfamiliar home.

Thus began the afterlife of a severe traumatic brain injury.

It was reading *I Am the Central Park Jogger*, Trisha Meili's uplifting story of healing and recovery after devastating injuries, including brain injury, that sparked the thought, a few years ago, that I, too, could and should write about my own experience. Trisha had spent several days in a coma after being brutally assaulted in New York's Central Park, and had to learn to read, write, walk, and talk again. Trisha's story also resonated with me because of the multiple connections we shared. She had attended Wellesley College many years before I did, but we shared an economics professor, David Lindauer, who was beloved by both of us. He had put us in touch when I began my recovery from my injuries, which were remarkably similar to hers. Also, we both worked on Wall Street and got our MBAs from the Yale School of Management. The following sentences from her book have stayed with me:

"Healing is the process of moving toward wholeness. Healing isn't becoming exactly the same as we once were. We move toward wholeness, certainly, through our physical health, but also through our emotional and spiritual health."

Reading Trisha's story stirred something deep within me, helping me to begin the slow journey to truly accepting and owning my limitations. If a woman like Trisha, who shares much of my background, could transform the tragedy that she endured into something beautiful, something everlasting, then what was stopping me? Despite the different contexts of our injuries, I heard echoes of myself reverberate from the pages of Trisha's book. But it would be another nine years before I began writing. The catalyst was Suleika

Jaouad's memoir, *Between Two Kingdoms*, another story of illness and recovery. Suleika's words flowed like vivid watercolors, painting the landscape of a life interrupted, inspiring me to create the time and space to tell my own story.

Straddling two worlds, that of India and the United States for many years, I've learned that while much of the experience of disability echoes across borders – even the most robust systems in the United States can crumble without warning – it is much, much harder experiencing a disability in India than in the West.

Though countless wonderful people here, as in the United States, carried me through my darkest days, and Western visitors marveled at the thoughtful care I received in Delhi, if one steps beyond the borders of my "village" – that magic circle of family, friends, and caregivers – empathy often dissolves into patronizing pity. This book seeks to piece together two parallel lives – the before and the after. And to communicate to readers that life for someone like me can still be beautiful. *Is* beautiful.

To write this book, particularly about the time I was in a coma in Uganda and India, I bombarded many of the people who appear in these pages with questions, and pieced my story together bit by bit. The details presented here of those moments are based on their accounts and are as accurate as reported. However, with their consent, I have taken some artistic license for crafting dialogue and scene-setting. Even while doing so, I have aimed to recreate events as faithfully as possible.

From Chapter 4 onward, the narrative primarily draws on my own recollections, thoughts, and feelings. However, when I was uncertain of the accuracy of certain details, I drew upon the memories of others to refresh my own.

The characters in my memoir have given me permission to name them, write about them, and quote emails, blogs, and so on, a few of which have been lightly edited for brevity. To protect the privacy of certain individuals, I have altered their names, but other details are intact, allowing this story to endure while respecting norms of confidentiality.

I would like to emphasize that what follows is *my* story. It should not be generalized to represent the experience of any other person with a traumatic brain injury (TBI) or disability. Every brain is unique, and the effects of every brain injury are distinct for each individual. Likewise, each person's journey with disability is their own, each being true in its own right.

1

An Ever-Burning Candle

It was a Friday. The mood in the office was light and breezy. Yet, nerves and excitement made knots in my stomach. I had recently started my new job in Uganda at the Bangladesh Rural Advancement Committee, or BRAC, a nonprofit organization with global reach, and had been consumed by work all week.

Outside, the sun, still a couple of hours away from vanishing below the horizon, beamed its unsparing rays upon the kitchen staff scurrying down the red dirt paths of the office compound, wrapped in their colorful traditional lesu.

Having moved out of my comfort zone to the breathtaking beauty of Uganda's capital city, Kampala, nestled amidst undulating hills and lush greenery, I sat in my chair, exulting at the prospect of the adventures that awaited me in this unknown land, thousands of miles away from home.

I often wonder if I would have done anything differently that day if I'd had some premonition that it would be the last day I would experience such lightness and ease for a long time. Might I have taken a break from staring at my laptop to soak up some sun with my colleagues? Booked a flight to return to my comfortable life in New York with my partner?

Or maybe – hopefully – hopped onto a matatu¹ to purchase a helmet.

The day had begun with a meeting with the visiting CEO of the US branch of BRAC, Susan Davis – a confident, middle-aged woman with short, brushed-back blonde hair. She had seemed surprised yet pleased when I'd sought her out in New York a few months earlier and told her I wanted to resign from my Wall Street job and work for BRAC in Uganda.

I'd approached her when the time finally felt right to begin moving out of the world I then inhabited, before it came to define me. It's difficult to overstate just how surreal that existence had become – to have the means not merely to live comfortably, but to party or frolic most weekends without a second thought about the thickness of my wallet.

Living in a shoebox-sized apartment in downtown Manhattan in your early twenties makes you feel you have it all. And yet, paradoxically, I often came home feeling incomplete, unfulfilled by days spent making rich people richer. I had always seen myself as creating a larger social impact than the smiles on millionaires' faces – I believed I was destined for the social sector. However, I remember feeling bewildered when I witnessed a bunch of women – my classmates – strutting around campus, their heads held high, decked out in business suits to interview for sought-after jobs. What was I missing? These women were smart, were they onto something that had escaped me?

A short while later, after some well-crafted emulation, I felt elated when I managed to get a job on Wall Street amid a global financial crisis; reveled in the thought of being able to afford to live in New York City, where my partner would also relocate. Though my days at Morgan Stanley gleamed with corporate polish, I kept my true compass hidden, but unwavering: I was there to study

the intricate machinery of private sector success, collecting tools that would one day serve a greater purpose. I gathered each lesson knowing I would reshape these silver spoons into something that could feed more than just profits.

In two years, I felt I had learned enough. If pivoting away from my current client base meant a big pay cut, so be it. I set my sights on working to help smallholder farmers in Africa – this became my pole star. It wasn't long after that I discovered BRAC, a global non-profit, uniquely headquartered in the Global South, in Bangladesh – working on poverty alleviation in some of the world's most conflict-torn countries.

I won't pretend I didn't have any wisps of doubt about the tradeoff I'd made, particularly in those final days after I'd put in my papers, when it was already too late. Was I really trading Morgan Stanley for BRAC? What doors might now stay closed?

And then there was Uganda – so far removed from anything I knew. Each passing day there brought new questions.

But after just thirty minutes of talking to Susan on the morning of October 8, 2010, everything clicked into place. Having her assure me of the endless opportunities that awaited me in Kampala and of the boundless potential she saw in me to create real impact did the trick. I had a challenge to scale.

As I walked out of the meeting, I spotted my colleague, Meri, a serene yet vivacious twenty-six-year-old Armenian, seated at her desk, her curly auburn hair flowing past her shoulders. Meri worked as a research associate at BRAC Uganda. She had worked with Susan at BRAC USA and the Center for Child and Family Welfare at Duke University in the US before coming to Kampala. The following day, October 9, was a holiday marking Uganda's Independence Day, and we had an extended weekend to look forward to, to cap off a hectic week.

I walked up to her and suggested that we kick off the long weekend festivities together at my place before we set out for the night. The tiny apartment I shared with our colleague, Saif, and his wife, Jouty, was a five-minute walk from the office in Nyanama, a sparse suburb about a thirty-minute drive from downtown Kampala. The couple were both Bangladeshi. Saif was my colleague at BRAC while Jouty worked at Nyumbani Decor, a furniture store in Kampala.

I had arrived in Kampala six weeks ago and had soon connected with an idealistic crew of young expatriates, mostly working on some form of poverty alleviation with various development organizations. The group I was part of had decided to meet to make the most of the long weekend. We had planned to begin with a barbeque at the home of a young man called Matt, and later, we intended to explore one of the many hotspots in a city I was still discovering.

There was one thing I needed to do before I left Nyanama for the evening – call Nikhil, my partner of the past five years. When I had taken a flight east to Uganda from New York, Nikhil had flown west to enroll at Stanford Law School, returning to the San Francisco Bay Area where he had spent most of his life. He only moved away in 2004, when he gained admission to Harvard University as an undergraduate. At the same time, I left India to study at Wellesley College, also in the Boston area. We met in 2005 and were inseparable.

Dhaval, my best friend at the time, like me, was also starting college at Harvard in 2004, and I would often spend time with him on the weekends. To be honest, it wasn't just Dhaval I wanted to visit but his charming male friends. With a (deserved) reputation for being easily smitten by the opposite sex – I had my first crush as early as the third grade – I was, in that sense, an unlikely candidate for Wellesley, the reputed women's-only liberal arts college that had offered me the best deal for undergraduate study. I had no regrets

about my decision since Wellesley proved to be an empowering place. But I longed for male companionship.

One weekend, Dhaval had invited me to a concert at which his band was playing. Students thronged the auditorium, and there was an energetic buzz in the air. Soon, the band started playing, the tempo of the music picked up, and the audience began moving to the beat. "My gosh!" I yelled, leaning closer to Alex, a close friend from Wellesley, to make sure she could hear me over the din. "The lead guitarist's solo is *fiiine*. He's so damn attractive, too!" I had been a fan of rock music since the age of fifteen when Dhaval introduced me to Led Zeppelin. Suffice it to say that I knew a good guitarist when I saw one. This one's finesse had me mesmerized.

Later that night, we went to a party in a cluttered dorm room, with music blaring from speakers of sub-optimal quality. Dhaval introduced me to his friend and bandmate: Nikhil. Soon, we were dancing and every time our bodies touched, my skin tingled, the sensation growing stronger as the night progressed until our lips finally met. He wasn't the best dancer in the room, but that was the last thing on my mind.

The more I came to know Nikhil, the more I felt pulled to him. I was fascinated by how lightly he wore his razor-sharp intellect, combining it with a surfer-casual demeanor vaguely reminiscent of the Dude from *The Big Lebowski*. He was majoring in Social Studies, a prosaic name for an exciting interdisciplinary major at Harvard, in which subjects like politics, economics, sociology, anthropology, and philosophy were applied to a narrow topic in your final dissertation. Nikhil, whose interests were wide-ranging even though he was a true child of the Bay Area, traveled to Egypt to conduct thesis research on the Muslim Brotherhood. He studied advanced Arabic, and researched and wrote on the transformation of modern Islam. As we grew closer, my friends became his, and

his mine. Our time together was filled with love, laughter, shared dreams, and endless shenanigans.

Now, in 2010, we had mutually agreed to pursue our individual paths while holding onto our relationship, with the shared belief that giving ourselves space to grow would strengthen our future together. The idea of putting our relationship to this test felt both terrifying and exciting. Could it really survive the miles between us? "If we're still together after a year of a long-distance relationship, we will get married after I graduate from law school," Nikhil had declared before I left. I remember wrapping my arms around him, imagining our wedding at the destination of my dreams – the Neemrana Fort Palace, a historic fort-turned-hotel in Rajasthan.

Nikhil and I would chat regularly. I felt a sense of incompleteness if even a day passed without his involvement in my life in some small way. Advice, commentary, feedback, conversation – I wanted any or all of it. Five years of togetherness that began when we were just eighteen had bound us tight to each other. This co-dependence felt almost innate. Sometimes we talked about the most mundane things. You could do that with Nikhil. He was both brilliant and utterly unpretentious. Perhaps his Punjabi-American roots shaped this blend. Most of his larger clan was spread across California, with some sprinkled far away in Florida. They combined American traditions and Indian ones with gusto. The centerpiece of their Thanksgiving feast was always a masterfully spiced tandoori chicken. Earlier that week, Nikhil had advised me to cook and freeze bulk quantities of keema (minced goat meat) after I told him that I'd bought some for lunch. On another day, I might have asked him to look up a couple of Kampala restaurants or bars for a fun weekend night with my friends.

"Bye, babes, have fun tonight," Nikhil said.

"Yeah, I really gotta go. I wish you were here," I replied. "Love you, Nicky," I added before reluctantly ending the call.

Meri, with an inexplicable sixth sense, had chosen to head to her own place to get dressed and run errands before our night out, giving me some alone time.

Now, I saw her approaching from the open landing outside my apartment. She warmly complimented me on my outfit – a navy blue dress with silhouettes of beige and white flowers, worn over black trousers, if I remember correctly.

As Meri and I chatted about who we might see that night, a sudden thought struck me: we hadn't invited Kizito Davis, a Ugandan man, whom one of our colleagues, Amar, had met a short while ago. They had met at the aptly named Good African Coffee – a sanctuary for English Premier League (EPL) fanatics – where both men had independently sought refuge, each hoping the coffee house would meet their expectations. But it didn't. The cafe wasn't airing the game they'd come to watch.

Two defeated fans. One shared obsession. In desperation, Davis led Amar to a nearby ramshackle structure, its roof made of corrugated iron. He insisted it was a church. Davis knew that the rickety building contained an unexpected treasure: a TV. Amar couldn't believe his luck. He'd found a local friend when he needed one most. To their surprise, entry was ticketed. But the fee was modest.

Within minutes, Amar and Davis were squabbling over which team would win, Manchester United or Tottenham Hotspur. Before Amar left Kampala, he made sure to introduce us to Davis.

I reached for my phone.

"Davis! What are you doing tonight?" I paused, then plowed ahead. "Oh, forget it, you don't have a choice. You're coming out with us!"

"Ah, trust me, I really want to," Davis sighed, "but I have to work..."

"Noooooo!" I wailed. "The night will be no fun without you."

I loved dancing and Davis was my dance partner in Kampala. I nagged him relentlessly until he agreed to join us. "Okay, now that's sorted, let's grab a boda to Matt's house," I said to Meri.

Boda bodas, or motorcycle taxis, are ubiquitous on Ugandan streets for the undeniable convenience they provide to passengers. It's not as if folks taking bodas are unaware of the numerous collisions they are involved in, sometimes resulting in grave injuries and even death. But such tragedies only happened to others.

Just that morning, I had sworn to my parents that I'd buy a helmet the following day and had really meant it this time. I had, myself, witnessed a boda accident just the previous Sunday, with a man rolling on the ground, shrieking in agony.

Despite my desire to purchase a helmet, I simply hadn't made the time during the hectic workweek, and I was in desperate need of a night out – read, buying a helmet was not top priority. That week, I went on a field trip to the rural hinterland of Iganga, located two hours away from Kampala, to visit a group of maize farmers BRAC was training through its agriculture program. As the program manager for agriculture interviewed them, I listened attentively, notebook in hand. BRAC's mission here was clear – to enhance farmers' livelihoods by forming informal groups, promoting fertilizer use, providing storage solutions, educating them on crop life cycles, and offering training. My role was to document these realities by crafting compelling fundraising proposals and concept notes for donors to secure the necessary funds for these critical projects.

I had been moved by the struggles of the women farmers I'd met. Even when I returned to the office, their words echoed in my mind. Despite their productivity, their frustration at being unable to

transport their bountiful harvest to the market was palpable. I found myself fidgeting with the plastic folders on my desk, overwhelmed with a feeling of helplessness. But then, I reminded myself that I had moved to Kampala for a reason – I must act, I told myself. After two days of brainstorming, I conceptualized a project for a bus service that would enable these women to transport their crops to market, alleviating their struggles and reducing market inefficiencies.

I was in the early stages of designing this new program, and it had consumed my mind. The thrill of providing a potential lifeline to the women I'd observed toiling under the sun filled me with a strong sense of purpose. I knew I had done the right thing by coming to Uganda. I was planning to spend a full year in the country at BRAC, after which I had ambitions of enrolling at a business school in the US which emphasized nonprofit management and social entrepreneurship. But it was my project I was focusing on, right now; the business school applications had taken a backseat.

As the sun set behind the hills, tinging the sky with a golden glow and illuminating Nyanama's bare landscape, Meri and I scurried to hail a boda.

After haggling with the third boda driver, we settled on a price that would get us to Kitante, an upmarket suburb of Kampala, without carving too deep a hole in our non-profit pockets. Even though the fare into Kampala in 2010 was only three thousand Ugandan shillings – less than one US dollar – the frequency with which we took bodas made haggling a necessity. Besides, price negotiations were expected when taking bodas.

The sun had dipped below the horizon, but the night was young. Meri and I had learned a hack that added a little extra fun to our boda rides while also saving money. Rather than each of us getting our own bodas, we had discovered that two people could share one. I hopped on behind Meri, feeling like a feather being swept up by

the wind as the scooter picked up speed. Meri whooped in glee and spread her arms wide like she was flying. We zipped into Kitante, and before long we were stepping into Matt's garden, where laughter and the smoky scent of barbeque greeted us.

Meeting such a diverse group of accomplished and passionate individuals in just the first six weeks filled me with a sense of hope and endless possibilities. Uganda was already shaping up to be more than just a place for meaningful work – it was becoming a place where I would surely make lifelong friendships.

With a quick hello to Matt – who seemed preoccupied with his hosting duties – we strolled over to a group assembled around a table, ready to dig into the food. Nearby, another cluttered table displayed an array of cheap liquor bottles. We tended not to splurge on alcohol. Because of the work we did, we were acutely aware of the pervasive inequality and poverty in Uganda, and it felt brash to buy expensive alcohol when the World Bank's estimate of Uganda's per capita income was a mere \$825 per year back then, in 2010.

I had been planning to organize a TEDx Kampala conference with Sujal, another of my new friends, an Indian American who was in Kampala to conduct scholarly research on psychosocial and cognitive rehabilitation for children with HIV/AIDS. Slim, with chiseled features and large eyes, he was personable, extremely intelligent, and fun-loving. I was now waiting for him to arrive so that we could discuss the theme and potential venues for the event. Soon, I spotted him chatting with others in the distance. Upon seeing me, he attempted to tear himself away from the group he was surrounded by. But just then, a couple of other muzungus² accosted him. I shrugged and moved on. He'd be back.

As I looked around, I saw several familiar faces. I waved enthusiastically to Eleanor, a young woman who worked at the Clinton Global Health Access Initiative (CHAI) in Uganda. She

was working on a pediatric diagnosis of HIV/AIDS at CHAI and was also managing teams from the US Agency for International Development (USAID) and the Centers for Disease Control and Prevention (CDC). I enjoyed her company because of her wealth of experience in global health and always cheerful demeanor. Eleanor pulled me into a hug. Sujal, who had finally managed to extricate himself from his fans, soon joined us.

As we chatted, Jack's booming voice erupted from behind me.

"Let's head to Just Kicking tonight." This was a sports bar with good music, and very popular with our lot.

Sujal turned around, cupping his palms around his mouth, forming a megaphone.

"An executive decision has been made. We are heading to Just Kicking! If anyone objects, speak now or forever hold your peace."

I fished out my phone from my bag and called Davis to find out where he was.

"I'll meet you at Just Kicking soon. I still have to finish working and close the shop," he said.

Like me, Davis was twenty-three years old at the time, his energy as infectious as his easy smile. He walked with a spring in his step. Slight of build, his boyish and good-natured appearance only added to his charm. He had grown up in a family of modest means, and had turned his studio apartment into a barbershop, which he began running when he was just sixteen.

Davis had become a breadwinner at a young age. After his father had passed away, his mother, a stay-at-home mom, struggled to make ends meet. Since money was short, Davis was forced to drop out of school in the sixth grade. Despite the weight on his shoulders, he never let it dim his spirit. He threw himself into our carefree adventures and frivolous activities. He seemed always to be brimming with the knowledge of how to navigate life's curveballs.

Meri and I had grown attached to him in the short time we had known him, and we were already thinking of encouraging him to pursue higher education.

After speaking to Davis, I made a call to Walter, the reliable boda driver who'd handed me his business card on a previous ride, promising us that safety was his utmost priority. Having availed Walter's services on several occasions, I asked him for his help ferrying me and my friends to Just Kicking. Soon enough, Walter arrived with his friend, Denis, another boda driver, and we got ready to navigate the lively streets of Kampala.