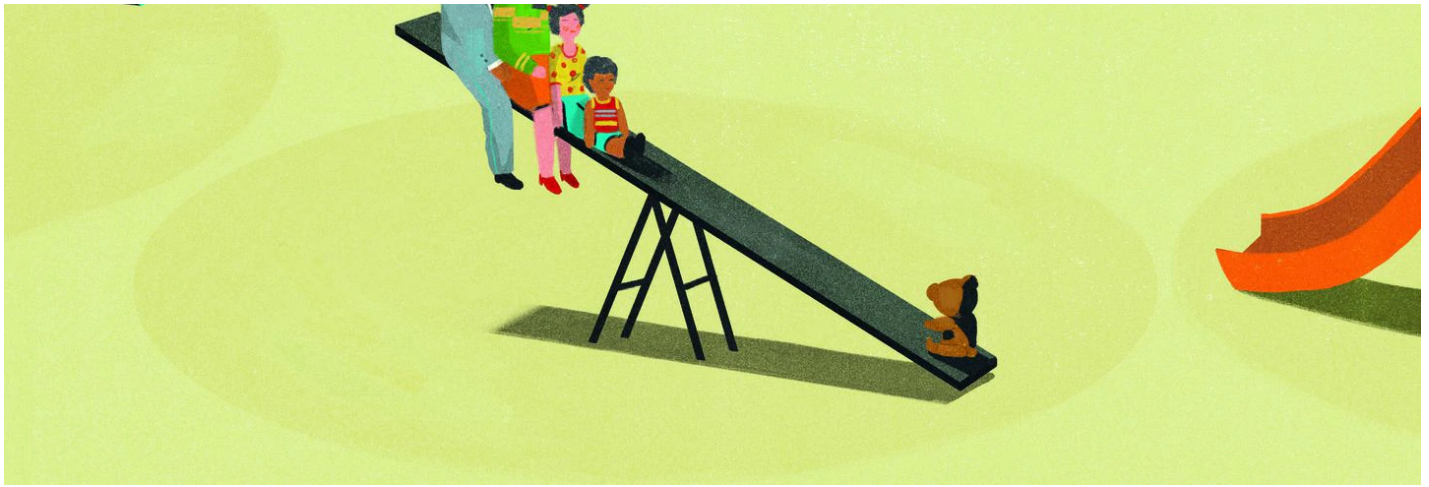


PRABAL CHAKRABARTI

# What we have lost we will find once again

By Prabal Chakrabarti May 31, 2019, 42 minutes ago





(FABIO CONSOLI FOR THE BOSTON GLOBE)

ON JULY 1, 2018, I traveled with my wife Vanessa and our eight year-old daughter, Anandi, from our home in Cambridge to Rajasthan, an Indian state on the border of Pakistan, to try to adopt a little boy with two club feet. He had been left under a tree outside the rural clinic next to the orphanage, we were told. Perhaps his family could not afford to care for her him or deal with his disability — correctible with a simple operation.

**A**fter a flight through Qatar, we arrived in New Delhi where we took a taxi from the airport through early morning traffic to the city's sprawling railway station. Porters in red shirts scurried over to carry our bags.

Since I'd last visited India two decades before, the country had become shinier, louder, and more polluted. Gone were the duck-like honks of bicycle rickshaws, replaced by buzzing scooters carrying two and sometimes three riders. There was less abject poverty, but laborers still carried bricks and shoveled dirt in the oppressive heat. I read about people in Rajasthan who left their homes that summer to sleep at night on the sidewalks to escape the heat, early victims of the changing climate.

We could lift a boy from this parentless fate.

We searched in the darkness for our train platform, and saw dozens of travelers

sleeping on the concrete. One family of five huddled together without a blanket or pillow. While I hurried past them, I envied their wholeness, their quiet propinquity.

My wife, daughter, and I had circumnavigated the world — physically together, yet asunder by unspoken grief. We moved with an intensity that belied an eerie numbness.

We were in India to radically change a young boy's life; I secretly hoped that this child — a complete stranger, someone who had come into this world with nothing — would save us, too.





(FABIO CONSOLI FOR THE BOSTON GLOBE)

Another seven hour train ride took us to Ajmer station, where we disembarked with a mass of pilgrims.

In India, every event is an excuse for ceremony — even the purchase of a new car merits a splashy burst of marigolds and rosewater. It now seems absurd, but when we arrived from America at this desert town, I was expecting flower garlands or the music of conch shells.

Instead, the taxi followed a long dirt road to an unremarkable green fence. The orphanage was on the outskirts of town; it was 112 degrees that day. Three peacocks ambled about in a dusty field nearby. We knocked on the door and an older man peered out suspiciously. He had no idea why we were there, and

asked us to sit and wait for the director. After a long delay, a sleepy child was brought out to us, wearing the new clothes we had sent.

We were given an hour to spend with him and forbidden from taking photographs. This moment would remain an undocumented memory. Anandi managed to stay awake to catch her first glimpse of what she hoped would become her brother but to the boy, we were nothing — just three more strangers among an endless succession of caretakers and children, coming and going.

The following day, Vanessa, her hair covered by a scarf, Anandi, and I — a Hindu — visited the inner chamber of a 13th century white marble Sufi tomb. Worshippers crowded in with us, praying and mourning in the stifling heat. In that ancient space, I felt a hint of the sublime.

I closed my eyes and thought I heard the voice of someone I knew and loved. I whispered back.

Two days later, we went to Indian family court to convince a judge to allow us to take the little boy to America. Inside the faded yellow courtroom, we joined a sea of humanity. The woman to our right was in tears, gripping her mother's hand.

A judge sat behind a large divided counter; we stared up at her. She spoke briskly to a clerk who typed away.

Then she turned to us: "Why do you want to adopt a child from India?" she demanded.

If I showed any hesitation, we would be lost. But I didn't trust my voice. For many years, we had loved and cared for our two daughters. Now Anandi rode in the backseat alone. We had never planned to adopt, but here we were in this courtroom on a week's notice.

I struggled to appear normal, disguising my apprehension as the normal feelings of an ordinary man adopting a child he didn't know, confused and bewildered by the adoption process in a foreign country.

But I wasn't normal. My heart was a muffled thing. Could the judge detect my subterfuge?

I stammered, "Because I am Indian."

“What about her culture?” the judge asked, pointing at my wife, who was born in France. “You don’t respect her culture?” Was the judge asking if I had forced my wife to do this?

Anger welled up inside me. Throughout the previous year, I had watched in awe as my wife channeled our loss into pursuing this adoption: the communication and paperwork; the notarized documents; the health forms; the home visits. Couldn’t the judge recognize her commitment?

“How do your other children feel about this?” the judge probed.

My other children.

I had always thought of myself as a lucky person — a recipient of a Marshall Scholarship to Oxford and professionally successful. But in this hot, dingy courtroom, I was reminded again of how much I had lost.

One day, three years earlier, our elder daughter Sajni told us that she was having trouble putting her pinky finger on her violin string. She was seven years old. Her pediatrician noticed that her eyes were not tracking together, and told us to get an emergency MRI.

We rushed Sajni to Boston Children’s Hospital. In the elevator up to the second floor, I recall seeing an ad proclaiming that the hospital was number one in the US News ranking. We would make it, I told myself, even if the news was difficult.

After Sajni’s MRI, the doctors took us into a private, windowless room. There was a box of kleenex next to a table, a sofa and two chairs. It was an ordinary room, but here is where my life changed.

The doctors told us that Sajni had an inoperable brain tumor called diffuse intrinsic pontine glioma, or DIPG. Sajni's tumor lay in the deep interior of the brain stem where all vital functions like breathing and heartbeat are controlled. The disease had a zero percent survival rate, and affects about 300 American children per year.

There would be no heroic neurosurgeon, no tense made-for-TV scenes followed by relief and joy. Indeed, there would be no hope at all. We're sorry. There is no cure. Nothing you do will keep her here.

Our beautiful, talented, compassionate daughter was given eight months to live.

Later, my wife described leaving her own body, watching us take in the diagnosis as if she were watching a movie.

Like all parents, we tried everything we could to save our daughter. We flew to England 10 times where a robot placed four catheters into Sajni's brain stem. Chemo drugs dripped into her brain-stem through a metal port until her limbs temporarily stiffened, signaling that the treatment needed to end.





Sajni (age 7) at Fresh Pond in Cambridge. December 2015. (FAMILY HANDOUT)

Later, she received the first synthetically personalized immunotherapy vaccine created for DIPG. She tried acupuncture and healing massage. I placed my hand on the back of her head and imagined the tumor melting away. I talked to a company about a kind of space helmet with magnetic rays. Vanessa brought her to more than 10 appointments, drawing quietly with her and Anandi (then five years old) in hospital waiting rooms.

Once, at Heathrow airport, Sajni's wheelchair broke. Running to make a train connection to Bristol in time for that evening's MRI, I dragged the wheelchair and Sajni, thrilled that I could finally do something tangible to save my daughter.

Sajni lived 19 months following her diagnosis and had more happy days than I would have thought possible. But at the end, when the EMTs arrived at our home, we had to tell them not to resuscitate her. I remember them looking at me, counting her pulse down.

We told her she was the best child we could have ever asked for. We held her, and she slipped away.

We did things to cope — raised money to test every drug ever made for efficacy against her disease, and to comfort sick children at the newly named Sajni Center in Amesbury. We also learned that astronaut Neil Armstrong had lost his two-year-old daughter to the same disease in 1962, seven years before he walked on the moon.



Like Armstrong, we kept moving. But unlike Armstrong, I could not set my sights on the moon. It was hard enough getting through each day.

At Mt. Auburn cemetery, the room looked like an admissions office — festooned with portraits; a cherry wood dining set; plush chairs, a thick bound artbook of the grounds in all seasons. I paid the amount I had saved for Sajni's first year of college to buy a family burial place. Some of America's finest are here, I thought bitterly. I had failed in my most basic responsibility as a parent.

Back home in Cambridge after our journey to India, we waited for the call.

With all the paperwork filed, the home visits finished, the testing done, I finally had time to wonder what it would have been like to go through this adoption with Sajni by our side. Full of life and endlessly curious, she would have loved India. I had wept at baggage claim when we first landed there: I had wanted so much for Sajni to see my native country and that moment, I realized she never would.

But in our rush to adopt, I had never asked whether Sajni wanted this for us.

There was a time when all of our children were alive on separate continents — Anandi running in Cambridge; Sajni determinedly pushing her walker, then wheelchair-bound; and our not-yet adopted son, crawling with club feet through the sandy, dry ground of Rajasthan. For six months, they were all living and breathing on Earth.

To have had Sajni, that is our treasure.

She would have understood the plight of the parentless boy. She would have wanted to help him.

Yes, I decided in the end, she would have loved this little boy.

Fifty years ago, after the loss of his daughter, Neil Armstrong walked on the moon. One night, when Sajni was nearly fully paralyzed by the tumor, I held her up on the back porch to help her peer through her telescope at the moon's Sea of Tranquility. In spite of her crippling illness, she smiled.

The moon is a barren rock, but it creates the tides, casts us in moonglow, and appears in different forms. Sometimes it reflects the warmth of a celestial presence. Like my daughter's memory.

And finally, we received good news from the desert.

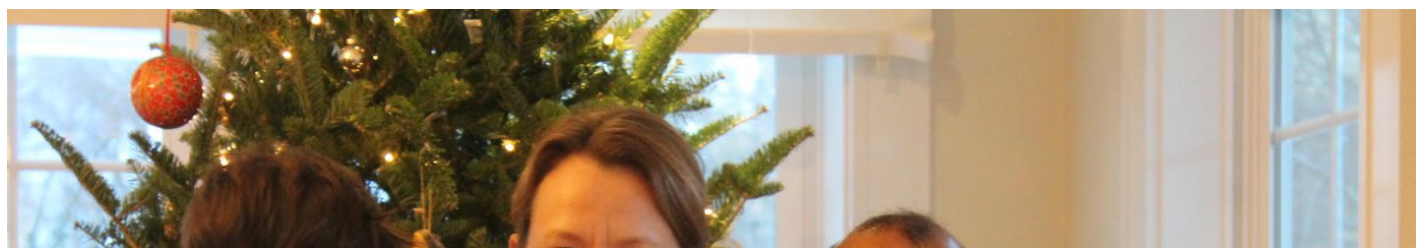
Six months ago, a small boy named Remi traveled across the world to become part of our family. Until he arrived, all of us were castaways, imagining the impossible: a way to rise above our grief, to find a family, to come home.

Today, Remi is two-and-a-half years old. He runs to keep up with his big sister. He knows some French and English, and retained a bit of Hindi. He loves pizza; Tom and Jerry cartoons; his music class in Belmont; and the municipal pool in Cambridge. He knows how to wave to catch the 72 bus to Harvard Square.

We curl up as a family on the bed to read stories.

Remi brings us joy. Even on the many days when we cry in private.

And he has learned, while ardently hugging Anandi, to point to the photos on the refrigerator of his other sister and say, with feeling, "Sajni."





Anandi (age 7); Remi (just turning age 2); Prabal and Vanessa soon after bringing Remi home. (CREDIT: FAMILY HANDOUT)

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In Sajni's legacy, Prabal's family support the Sajni Center of Lucy Love Bus and the Sajni Fund for DIPG Research at the Broad Institute of MIT/Harvard. He resides in Cambridge, and is a senior vice president at the Federal Reserve Bank of Boston.

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