The Downside of Hope
By Darshak Sanghavi

INTRO:

As a physician and writer, Dr. Darshak Sanghavi knows how important hope is for families facing serious illness. But when illness affected his own family, he learned that hope can be a mixed blessing.

COMMENTARY:

“Hope,” writes poet Emily Dickinson brightly, “is that thing with feathers that perches in the soul.” But I’ve learned that hope also has a dark side, and can be an intoxicating, maddening thing to people in crisis.

Years ago, my father’s lungs were progressively scarring from a rare disease, and he survived only with a plastic mask and tube that connected him like an umbilical cord to an oxygen tank. Only a lung transplant could save him, and even that wasn’t a perfect solution. One surgeon from Johns Hopkins explained ruefully that a transplant would hopefully replace a set of very serious problems with a slightly smaller set of very serious problems. Worse, no lungs were available, probably for years.

One night at my parents’ home in New Jersey, Anil Merchant, my dying father’s best friend, suggested that we canvass rural India to find some indigent man who might give his lungs to my father—if we were to negotiate the right price with the man to ensure his remaining family’s comfort since he would of course die. The fact that Anil wasn’t kidding showed our desperation.

Of course, my sister and I—both doctors—quickly rejected Anil’s plan to buy human lungs. Whatever bartering in lives that happened in India, a land where everything—including one’s lungs—may have a price, certainly wasn’t acceptable in the United States.

But my enlightened notions were tested a few weeks later, when I received an urgent page at the hospital on the rural Navajo reservation where I worked. It was my father.

He’d heard a young Indian man had been in a serious car accident and was reportedly brain dead somewhere in Baltimore. Indians are a surprisingly interconnected ethnic community; almost any person can be related to another by a few degrees of separation. My dying father asked to take advantage of that network. Could my sister and I somehow find this poor man’s family—they surely knew us somehow—and talk them into donating the lungs directly to my father?

With a surge of hope, I began working the phones immediately. I called every intensive care unit in Baltimore, beginning with Johns Hopkins Hospital. “This is Dr. Sanghavi,” I said to the charge nurse in the intensive care unit. “Did you happen to admit a young
Indian male after an M.V.A. (a “motor vehicle accident”) with massive intracranial trauma?” She said no. I expanded the search to outlying and suburban hospitals. In parallel, from her hospital in Boston, my sister called ICUs in Washington DC. I moved on to Delaware, then Virginia, and even Philadelphia, fingers flying over the phone keypad.

I was being completely irrational.

I don’t know what I would have said to the poor man’s family. I wasn’t thinking about how I selfishly put my father’s health above some other person on the waiting list, the risks of surgery, or the fact that my father hadn’t even completed his initial work-up for a transplant surgery. I was seized by the vision of my father, healed, one day holding a grandchild. It pushed everything else away. Isn’t that, after all, the essence of a dream—that it is pure in its idealism, and thus, the seed of triumph?

But after hours, my sister and I couldn’t find the man, and never got to ask his grieving family for his lungs. A few days later, we learned through the grapevine that the story was true—but the man died in western Pennsylvania. The family did donate his organs, and somebody else got his lungs. It turns out we did know the family distantly, but we never contacted them afterwards to ask what might have been. Better not to know, we decided.

My father never got a transplant, and died a few months later.

Afterwards, my hopes for my father changed. Before I hoped for the transplant, and now I desperately hope that he was better off without it. He had died without pain; maybe he would have suffered more from bad complications if the transplant went poorly. At least I don’t have that guilt. I truly believe now that everything was for the best, though I still miss him terribly.

In the end, I found that hope follows the arc of one’s own life: It begins as has an immature, impulsive thing that is prone to grandiosity and is not respectful of others. With time, it grows into an entity that is more complicated, bittersweet, and thankfully, more forgiving of failure.

OUTRO:

Dr. Darshak Sanghavi is an assistant professor of pediatrics at the University of Massachusetts Medical School and the author of A Map of the Child: A Pediatrician’s Tour of the Body. His website is www.darshaksanghavi.com.