Living Kidney Donation: It's Too Hard to Do Good

When I first called the phone number in the newspaper I knew it was a long shot. It is highly unlikely that any particular stranger will match to donate a kidney to a specific patient. But I wanted to try.

The story resonated for me. Even though we had never met, the woman in the article felt familiar. She was in her mid-50s, not that much younger than I was. She had two grown children, just like I did. While she now lived in Ft. Lauderdale, she had grown up in Kansas City, where I had lived for the past three decades. She had been part of the Jewish community where my family was very active. And her photo, bright and smiling, reminded me of my cousin Ann.

Fifteen years earlier my beloved relative had received a kidney from a dear friend, giving us all many more years to enjoy together. I knew firsthand what a donated kidney could mean for a family.

Now that I was retired from full-time work and my own children were fully launched I thought this might be the right time to try to pay that gift back.

Miraculously, I was given that chance; I was a near-perfect match. The ensuing 9-month journey, culminating in my successful kidney donation at the Mayo Clinic in Rochester, Minnesota on September 28, 2018, was extraordinary. I was privileged to observe and benefit from some of the most magnificent medical care in the world.

From the day I learned I was a match, I felt that my health and safety were a priority for the transplant center. The medical work-up and psychological evaluation were designed to protect me, both physically and emotionally, and I felt that I could confidentially back out at any time, without pressure or repercussion. My surgery went well, and I was out of bed and walking within hours. I was able to leave the hospital after two nights, and the rest of my recovery went smoothly. Four weeks later I was able to join my husband on a trip to New York City, walking miles to visit friends and staying up late for two Broadway shows. Today, more than three years after my donation, I remain healthy, with strong kidney function.

That is what matters most, of course. Donating a kidney did not hurt me. It did not make me worse off. It made me happy, grateful, and overjoyed that I was able to save a life.

But it was also not easy. In fact, it was so difficult that I cannot imagine how anyone without my life advantages—retired from full-time work; no child care responsibilities; a committed and available caregiver (my husband); the ability to advocate for myself; the financial resources to front the cost of travel, hotels, restaurants, and pet sitters—could possibly navigate the logistic, psychosocial, and financial barriers I encountered.

After hearing multiple times that “kidney transplants are scheduled at the convenience of the donor,” I ran into immediate problems scheduling my 3-day evaluation at the transplant center. While they were able to coordinate most of the necessary appointments for my 3-day evaluation, one sticking point remained. On the original donor survey there was a trick question: “Have you ever used recreational drugs?” I answered honestly: yes. Like most of my generation, I had smoked the occasional joint.

This turned out to be an immediate red flag. Before the clinic would even test my blood for HLA tissue typing I had to agree to see a substance abuse counselor if I matched and chose to proceed. I agreed; it seemed silly to stand on principle (recreational cannabis was legal in eight states and the nation’s capital). But there were no available appointments for the week I was to be evaluated. I would have to make another 12-hour round trip to the clinic, at my own expense, to meet a substance abuse counselor.

I protested vehemently, eventually talking my way out of the extraneous appointment. But what if I had not been a middle-aged, upper-middle-class woman, who spoke English as a first language, who was used to advocating for herself? What if I had not been White? How much privilege did it take to skirt this stigmatizing and definitely not convenient requirement?

There were many other times the clinic asked me to do things that were inconvenient. Days before my file was to go to the selection committee, they asked me to send my most recent mammogram, Pap smear, and colonoscopy results. I had been having frequent interactions with the clinic since I matched, including three days of in-person appointments for my evaluation. Why didn’t they ask for those results during any of those interactions, instead of springing this on me at the last minute, forcing me to cancel a day’s plans to run around town to gather the needed documents?

Once again I wondered how someone employed full time, possibly without flexible hours, could have gotten that done.

By the time I successfully donated, I had spent over $5,000 in out-of-pocket expenses, graciously reimbursed by my recipient. My husband missed 16 days of work to help with my evaluation, surgery, and recovery. He had a high-level job with sufficient paid time off, but what about potential kidney donors and their caregivers who don’t?

I could list many more examples of how donating my kidney was hard—too hard. Perhaps that is why
only 15% of potential living donors proceed all the way to transplantation. We desperately need more living kidney donors. More than 12 people die every day on the waiting list. Every kidney transplant saves private insurers or Medicare more than $150,000 over the lifetime cost of dialysis. Why can’t we invest some of that savings to reduce the barriers facing living donors? No one should have to work this hard to do a good deed.

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Ms Gershun is a writer and consultant to not-for-profit organizations living in Fairway, Kansas with her husband Don Goldman. Her most recent book, Kidney to Share (Cornell University Press, 2021), with coauthor John Lantos, MD, details her experience donating a kidney at the Mayo Clinic to a woman she read about in the newspaper. She is a Special Advisor to the Kidney Transplant Collaborative.

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CALL FOR SUBMISSIONS

“A doctor, like a writer, must have a voice of his own, something that conveys the timbre, the rhythm, the diction, and the music of his humanity, that compensates us for all the speechless machines.”
—Anatole Broyard, Intoxicated by My Illness

In this space, we hope to give voice to the personal experiences and stories that define kidney disease. We welcome nonfiction, narrative submissions focusing on the personal, ethical, or policy implications of any aspect of kidney disease in adults and children (acute kidney injury, chronic kidney disease, dialysis, transplantation, ethics, health policy, genetics, etc). Submissions from physicians, allied health professionals, patients, or family members are encouraged.

Types of submissions for this feature include essays of up to 1,000 words; short poems; or original visual art accompanied by 1-2 paragraphs of text. In submissions that refer to real patients, the patients must either be unidentifiable or approved by the patient(s) described.

Items for consideration should be submitted online at www.editorialmanager.com/ajkd.