

New York Has World-Class Hospitals. Why Is It So Bad for People in Need of Transplants?

New York has the lowest rate of organ donor registration in the country. Thousands languish on wait lists, and hundreds needlessly die every year.

By Ted Alcorn

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Kehinde Majekodumi does not look desperately ill. A vibrant 24-year-old, she bears little outward sign except a scar beneath her collarbone where a catheter was once inserted.

But three times a week she deviates from her regular commute between the apartment she shares with her twin sister and her job in a university admissions office to a dialysis center in East Flatbush, Brooklyn.

There she spends four hours hooked up to a machine that substitutes for her failing kidneys. As it removes waste products from her bloodstream, it can induce terrible cramps, and each session leaves her weary and nauseated. But it is all that is keeping her alive.

“Unless I tell people, they don’t know,” Ms. Majekodumi said. “I don’t mind telling people, but I don’t want that to be the thing they know me for.”

She is one of around 8,500 New Yorkers with organ failure who are currently awaiting the only treatment that can meaningfully change their lives — an organ transplant.

And as a consequence of where she lives, she will likely have to wait longer than transplant candidates elsewhere in the United States. That’s because that while the city boasts world-class hospitals and transplant surgeons, New Yorkers donate organs at a lower rate than anywhere else in the country.

The situation in New York has become so dire that federal regulators have taken notice: Last month, the Centers for Medicare and Medicaid Services informed the local organ procurement organization, LiveOnNY, that it was failing to meet minimum standards of performance and threatened to let its certification lapse so another organization can take over the area. LiveOnNY can still appeal the decision, but if upheld, it would be the first and only instance of an organ-procurement organization being shut down by the government under the current oversight rules, which Congress enacted in 2000.

Experts say New York City’s persistently low organ donation rate is the product of many factors, and replacing LiveOnNY alone might not make a difference. But that doesn’t lessen the stakes for Ms. Majekodumi or other New Yorkers awaiting transplants. Hundreds of patients in her circumstance die each year because of the delay.

These deaths are particularly vexing because they are preventable, said Aisha Tator, executive director of the New York Alliance for Donation, an advocacy group. “These people were not waiting for medical miracles,” she said. “We know what would save their lives. Those people could and should have been saved, and they weren’t.”



“Unless I tell people, they don’t know,” said Ms. Majekodumi, 24, wearing blue in the back while at church with loved ones, of her condition. Kholood Eid for The New York Times

The shortage seems to fly in the face of New York City’s reputation as a progressive hub.

“New Yorkers are generous on many levels,” said Dr. Devon John, chief of transplantation surgery at SUNY Downstate Medical Center in Brooklyn, where Ms. Majekodumi is a patient. Recalling a fatal fire in the Bronx last winter and the outpouring of donated food and clothes he

saw at a community center in its wake, he said: “We respond when it’s dramatic. But it’s the boring that sometimes needs the most attention.”

When the first organ, a kidney, was successfully transplanted from a deceased donor in 1962, it was viewed as a medical miracle. But transplantation quickly became the standard of care for people suffering from organ failure, and the growing need for transplants prompted efforts to promote and coordinate organ donation among the general population. Congress ultimately formalized a system for doing so that carves the United States into 58 distinct areas, each led by a nonprofit organ-procurement organization. LiveOnNY is responsible for New York City, Long Island and parts of the Hudson Valley. It has a full-time staff of 215 and an annual budget of about \$35 million.

In addition to educating the public about organ donation, LiveOnNY and its peer organizations are responsible for approaching the relatives of potential donors and making the delicate request. They also work with hospital staff to ensure that organs from consenting donors are procured and transferred to the patients who need them.

The work requires sensitivity but also speed because the window of opportunity is fleeting. As soon as death occurs and blood flow ceases, organs begin to deteriorate.

New York’s struggle with low rates of organ donation is not new. So-called deceased donations in the New York area peaked at 322 in 2007, but in subsequent years the number skidded downward.

One needn’t look far to find a community where organ donation is thriving. The neighboring organ procurement organization Gift of Life, which operates in eastern Pennsylvania and areas of Delaware and New Jersey, covers a smaller population but recovers organs from nearly twice as many donors. Among other factors, Gift of Life attributes its success to supportive local hospitals and transplant centers.

While it’s difficult to precisely gauge the scale of missed opportunity in the New York area, David Goldberg, an assistant professor of medicine and epidemiology at the University of Pennsylvania, has made some estimates. He said that if the New York area donated organs at a rate similar to the best-performing areas in the country, “there could be 100 to 200 more donors per year.” A single donor can provide transplants to as many as eight people.

LiveOnNY nearly lost its certification once before, in 2014, when it operated under the name New York Organ Donor Network. It was the first time the Centers for Medicaid and Medicare Services had ever charged an organ procurement organization with failing to meet requirements. The network appealed and was ultimately allowed to keep its certification as long as it adhered to a performance improvement plan. It also reshuffled its staff and adopted the name LiveOnNY.

But there is little evidence to suggest much has changed. The share of families approached by LiveOnNY who consented to become donors fell between 2014 to 2017, from 50 percent to 41 percent, according to internal data. An uptick in donors in the last three years is mostly accounted for by a surge in drug-overdose deaths, which is boosting the number of organ donors across the country.

Because local patients get preferential access to organs donated in their region, those most affected by New York City's deficit are New Yorkers themselves. Dr. John, of SUNY Downstate, said that while transplant candidates elsewhere might wait four years before receiving a new kidney, his patients wait as long as eight, a period in which their health continues to deteriorate. "The mortality rate of five years of dialysis is about 65 percent to 70 percent," he said, "the equivalent of brain cancer."



Yahaira Gonzalez, a medical coder at SUNY Downstate, was in her teens when her kidneys first failed. Two and a half years later, after several transplants that did not take, she was matched with a donated kidney from Connecticut. The transplant was successful. Kholood Eid for The New York Times

The long wait pushes some New York patients to seek transplants out of state. In 2014, when Yahaira Gonzalez needed a transplant, she was not naïve to the system.

Now a medical coder at SUNY Downstate, she was in her teens when her kidneys first failed and she wound up receiving a transplant. Later, when her body rejected that organ, her brother gave her one of his own. So when that kidney failed as well, and she rejoined the New York wait list, her doctors also encouraged her to research options elsewhere.

To join an out-of-state wait list, a patient must travel there for what can be a costly evaluation, a deterrent for poorer patients. But it may vastly reduce their wait. Ms. Gonzalez got listed in New Jersey and Connecticut, and two and a half years later, she was matched with a donated kidney from Connecticut.

Patients insured by Medicaid, like Ms. Majekodumi, may encounter additional obstacles to seeking care beyond the state's borders. Gregory Allen, policy director for New York's Medicaid program, said there are no legal barriers to getting transplants outside the state, but facilities must first enroll with the program, a burdensome process dictated by federal rules. "A lot of out-of-state facilities don't want to jump through the hoops of getting enrolled," he said.

So the poorest New Yorkers have little alternative but to stay put and wait.

Most people, if they think about organ donation at all, might pull out their wallets to display identification cards indicating they are on the state donor registry. But only a minority of New Yorkers can do so: just one in three residents are registered, the lowest rate of any state and a full 20 percent below the national average.

While the situation today is grave, it used to be worse. In 2012, shortly after Gov. Andrew M. Cuomo took office, fewer than one in five residents were registered. Long after other states had developed simplified online portals, New York required a cumbersome sign-up process that advocates say depressed rates of registration.

The Cuomo administration has enacted a number of measures to ease registration, including a law opening the process to 16- and 17-year-olds, the age at which they begin seeking driver's licenses, and putting the choice to people when they register to vote or sign up with the state's health insurance exchange.

The efforts have yielded an increase. State data show that since Dec. 31, 2015, more than 1.3 million New Yorkers have registered as donors, most of them 35 or younger. But people from 40 to 60 are registered at lower rates, and substantially expanding the registry will require reaching them. Around 10 million New Yorkers remain unregistered.

Those people still have the opportunity to donate, but under more fraught circumstances, when the choice is posed in hospital intensive-care units by LiveOnNY employees like Leslie Snead. When doctors can do nothing more to save a patient's life and they are identified by the hospital as a potential organ donor, Ms. Snead or her colleagues approach their relatives and make the ask.

Like many staff at LiveOnNY, Ms. Snead is driven by a personal connection to transplant. When she was living in Virginia in 2006, her 15-year-old stepson, Robert, got his learner's permit and checked a box indicating he wanted to be an organ donor. Four months later, while riding as a passenger, he was involved in a fatal car accident. His donated kidneys changed the lives of two people who had been desperately waiting for them.

Dr. Raghu Loganathan, who directs critical care services at St. Barnabas Hospital in the Bronx, spent an hour resuscitating a patient's heart so that it would continue circulating blood to the other organs so they could be donated.

Kholood Eid for The New York Times

“Organ donation saved my family,” Ms. Snead said. “For the last 12 years, we have been able to celebrate the lives he saved and not just be sad because he’s gone.”

Ms. Snead’s family had the benefit of knowing they were honoring the boy’s wishes. In New York City, where patients are less likely to have registered in advance, the choice is shaped by when and how their family members are approached in the hospital.

It is as much an art as a science. In surveys of public attitudes, most people say they would authorize donation from a deceased family member, but in the period of shock and crisis, a misstep may cause the family to decline. And LiveOnNY staff members by law get only one chance to ask.

So Ms. Snead has learned to read the emotional state of the grief-stricken families she encounters.

She recalled a recent case: a man in his 20s who was in a car accident and lost all brain function. Ms. Snead said she recognized that the mother needed more time to process her son’s death, and she held off an extra day before prompting a discussion about organ donation.

“I always know that the family is getting it when they’re standing around the bedside and laughing and sharing stories.” When she finally broached the subject, the mother said yes.

Such donations, she said, are affirming. But in the New York area, these conversations are more likely to end in a denial. According to LiveOnNY data, last year nearly two-thirds of the people they approached declined to donate — 579 potential donors who together could have donated thousands of organs.

According to Laura Siminoff, dean of the College of Public Health at Temple University, each family’s decision is shaped not only by what happens in the hospital room but also “by how connected they feel with their society at large.” A legacy of alienation from the health system can pose a significant obstacle. Among Asians, who as a group donate at the lowest rate in New York City, different cultural beliefs about death may be an obstacle; African-Americans also donate at lower rates.

When Ms. Gonzalez received her transplant, it inspired some of her friends to register as organ donors, but she said misinformation and mistrust stifled that impetus in others. One acquaintance heard a false rumor that emergency responders make fewer efforts to save the lives of victims designated as organ donors. “So that person basically went right back to the D.M.V. and removed themselves from the organ donor list,” she recalled.

Some of these barriers may be addressed by demystifying the donation process and elevating the stories of transplant recipients in their community. But that means changing attitudes outside the hospital, far before people arrive, and it’s not clear LiveOnNY has a plan to shift those numbers.

When LiveOnNY appealed its decertification in 2014, it argued that the city’s “particular ethnic mix creates special disadvantages for the organ procurement enterprise,” citing lower rates of organ donation among Orthodox Jewish and Chinese communities, among others. As a part of its performance improvement plan, the organization promised to change the way it reaches out to both groups.

It is the job of Leslie Snead to approach the families of patients who have been identified as potential donors. She has a personal connection to her work: Her 15-year-old stepson, who died in a car wreck, was a donor. “For the last 12 years, we have been able to celebrate the lives he saved and not just be sad because he’s gone,” Ms. Snead said.

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Regina Lee, a former board member of LiveOnNY who is now executive vice president of the Charles B. Wang Community Health Center, which operates at sites in Manhattan and in Flushing, Queens, helped oversee LiveOnNY’s outreach to the Chinese community and continues to partner with them in her current role. But she said the efforts faltered when funding ran out and the sole bilingual outreach worker left for another job. “We haven’t been able to move the consent rate, for whatever modest effort we’ve put in,” she said.

LiveOnNY has also been hampered by uneven engagement with the region’s hospitals, which play a crucial role in any successful donation. Intensive-care units must flag potential donors well in advance of death so family consent can be secured, and then it’s up to hospital staff to maintain the viability of the organs until a transplant program is ready to recover them. But clinicians in New York say that local hospitals have not historically held organ procurement among their top priorities.

Dr. Raghu Loganathan, who directs critical care services at St. Barnabas Hospital in the Bronx, said that during his training two decades ago, clinicians viewed a potential donor who had been declared brain-dead as “an orphan patient,” the responsibility of the organ procurement organization rather than the hospital’s.

Increasing organ donation requires a fundamental shift in perspective. To illustrate, Dr. Loganathan recalled a night when a brain-dead patient went into cardiac arrest. He and a team of other clinicians spent an hour resuscitating the patient’s heart so that it would continue circulating blood to the other organs and they could be donated, the kind of intensive intervention that trainees might assume only a living patient merited.

“We used to focus on the patients where there is a ‘prognosis,’” he said. “And that culture has changed, but not necessarily across the board.”

The Greater New York Hospital Association acknowledges that some hospitals have been less supportive of donation than others. Lorraine Ryan, a senior vice president of the association who is also a member of LiveOnNY’s medical board, said that while New York has some of the country’s premier transplant programs, they have not always shown an equal commitment to procuring organs in their intensive-care units. “It was the community hospitals,” she said, “that were outperforming the transplant centers themselves.”

In October 2017, the association gathered participants from all the area's large health systems for presentations, like one titled "The Current Crisis," and has circulated data showing hospital leadership how their performance compares.

Whether this will be sufficient to keep LiveOnNY in business is up to federal regulators. If LiveOnNY loses its certification, a neighboring organ procurement organization, like Gift of Life, could apply for the contract. Leaders in the field say that while depressed organ donation rates in New York may stem from many factors, responsibility ultimately has to lie somewhere.

"If I can't engage the hospitals and inspire them and motivate them to actively participate in donation, and we are not performing at the expected levels, the buck has to stop with our leadership," said Tom Mone, who heads OneLegacy, an organ procurement organization in Southern California.

In the meantime, patients struggle on. Ms. Majekodumi has been on dialysis for two years. She most likely still has several more to go.

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