

City & Region

# Organ transplant recipient is now an advocate for recruiting donors



Tom Jasinski talks about obstacles to registering as an organ donor in New York, which is second-to-last nationally in its number of registered donors (last is Puerto Rico). Jasinski started an organization to boost registration and donation after his experience as a transplant recipient.

By **Henry Davis** | News Medical Reporter | [Google+](#)  
on July 9, 2016 - 5:43 PM

When Tom Jasinski felt a slight pain in his chest and labored to breathe a few days before his wedding reception, he chalked it up to gaining weight.

So when he saw a doctor, just to be sure, his diagnosis came as a shock. His kidneys were failing.

Jasinski quickly found himself hooked up to a dialysis machine he would need for nearly four hours every other day to remove waste and fluids from his body until he got a new kidney.

He made it to the reception in a daze – his life turned upside down – and on the start of a long, anxious path toward an organ transplant. And that’s when he confronted a frustrating reality. A huge gap exists between the number of people who support organ donation and the number of people who register to be a donor.

New York State ranks 51st out of 52 donor registries, above only Puerto Rico, for the percentage of adults who are designated donors, according to the most recent survey by the advocacy group Donate Life America.

The national average is 50 percent based on 2014 data, according to the group. Montana ranked highest, with 86 percent of its residents registered. New York lagged at 23 percent.

“It is easy to become discouraged,” said Jasinski, 55, of Amherst. “The statistics are disheartening.”

Jasinski eventually got a transplant, but many others don’t.

The state has the second-longest list of patients waiting for an organ: more than 10,000.

Last year, nearly 1,000 people died or became too sick for a transplant while they waited.

“There are so many barriers,” said Aisha Tator, executive director of the New York Alliance for Donation. “We are moving a mountain in New York, but we are also showing results.”

Jasinski’s experience made him determined to do something about the lag in registered donors. He founded an organization known as One8Fifty to boost the numbers.

The name resonates with prospective transplant recipients.

They know that organs from one donor can save the lives of up to eight people, and the tissue and eyes from the same person can aid as many as 50 others.

“People don’t fully understand the dynamics of transplantation, how many lives can be helped,” Jasinski said.

## ‘Lack of awareness’

Organ donation advocates have their work cut out for them. There are signs of progress, although critics complain that it is too slow.

A new law will allow New Yorkers to register to donate on applications for coverage in the state’s health insurance exchange.

A bill, if signed by Gov. Andrew M. Cuomo, would allow 16- and 17-year-olds to enroll in the registry, while giving their parents authority to rescind the donation if death occurs before the potential donor turns 18.

Lawmakers in the past two years reformed and extended legislation that prohibits a driver’s license application from being processed unless the organ donation section is filled out.

There is good reason for the focus on driver’s licenses.

As in other states, it is through the Department of Motor Vehicles that most people sign up to be an organ donor. The DMV accounts for more than 80 percent of the registrations in New York.

What accounts for the overall poor showing?

Tator says one reason is the large number of people, especially in New York City, who don’t drive. Another is the eight-year renewal cycle for driver’s licenses.

She and others have identified several steps to improve the numbers: simpler registration, greater use of social media and software apps, and more places, such as public college applications, where the question can be asked.

“There is a lack of awareness. It’s not on people’s radar,” Tator said. “We need to make it a cultural norm, like wearing a bicycle helmet.”

## Days on dialysis

Jasinski was riding high in 2010. The branch manager at a staffing company remarried that year after the death of his wife.

He was embarking on an exciting new chapter of his life.

Then came the diagnosis. Suddenly, he was spending his days on dialysis, and placing his name on transplant lists in Buffalo and Cleveland.

He recalls sitting in the dialysis clinic, surrounded by other patients who seemed to be fading away as they waited for an organ.

There was too much time to dwell on the negative. The process itself made him think of the ancient practice of bloodletting. It didn’t help that his relatively uncommon blood type, B, lowered his odds of finding a suitable donor. He was told it might take 10 years.

He and his wife, Ginny, tried to stay optimistic. Just keep the faith, they told themselves.

Indeed, nationwide, more than 121,300 people remain on waiting lists for a transplant, usually a kidney. The United Network for Organ Sharing in 2015 reported there were about 6,000 organs available from living donors and 10,000 from deceased individuals, nowhere near enough to meet demand. Meanwhile, the waiting lists keep growing longer.

For Jasinski, things went from bad to worse.

A seemingly minor irregularity in 2011 on a cardiac stress test brought another shock. He needed triple bypass surgery to clear partially blocked arteries around his heart.

Jasinski still shakes his head at the irony. His heart was on the verge of killing him. But if he hadn’t needed a new kidney, he would never have known.

“I would have probably blown my heart out,” he said.

Like so many who wait, Jasinski preferred an organ from a living donor. Individuals had volunteered to be tested for their suitability, but never followed through, so he learned not to get his hopes up.

Then, he got lucky. In April 2012, Ginny’s cousin, Paul Broderick, got tested and turned out to be a good tissue match. Surgery was set for the fall.

Nearly two years after Jasinski’s diagnosis, their surgeries took place at Buffalo General Medical Center. Afterward, Jasinski remembers how they lay in the recovery room, trading text messages about country music and sports. The men formed a lasting bond.

“I will always be in his debt,” Jasinski said.

His experience made him a passionate advocate for organ donor registration.

Through his new organization, he’s trying to increase public attention to the need to boost organ donation.

## Fear and inaction

Why don’t more people register as donors? Doctors, researchers and advocates have wrestled with that question for years.

Most Americans support the general idea of organ donation, but studies suggest they feel differently when it gets personal – when they consider whether they should be the donor. Like adoption, people may see it as a good thing, but just not for them.

There is also no immediate reward for registering as a donor, and the act itself brings up uncomfortable thoughts of death, making it easy to procrastinate.

“People just aren’t motivated to do this,” said Jason Siegel, a Claremont Graduate University social health psychologist who studies donor registration.

Among other obstacles, Siegel said many potential donors hold unfounded fears that doctors will let a patient registered to donate die prematurely to obtain their organs.

“This is a core fear we find in research that rational thought can’t seem to break through,” he said.

Many efforts have focused on motor vehicle bureaus, taking such forms as public awareness campaigns and employee training. Earlier this year, Erie County Clerk Chris Jacobs reported that the number of willing organ donors in the county had grown as part of a Donate Life initiative – coordinated with Unyts, the region’s organ transplant organization – to train Auto Bureau employees on the significance of organ donations.

The DMV provides a location to routinely engage the public. But this place can be a source of anger, frustration and boredom, which, as one study put it, impedes registration.

Siegel and a fellow Claremont organ donation researcher, Eusebio Alvaro, say the best strategy may be a simple one: Inform people in a focused way and a positive environment, and get them to register immediately afterward.

The researchers ran an experiment, conducting organ donation presentations and then asking some groups to sign up for donation afterward. They asked others to take a donor card home and mail it back.

“For the cards collected after the information sessions, we got about half the people to register. For the folks who got cards to mail, we got practically nothing, zilch,” Alvaro said.

Jasinski wants One8Fifty to be a louder voice, identifying best practices and demanding progress at a faster pace.

“We’re moving – but glacially,” he said, citing the nearly 500 people in the state who died last year while waiting for a transplant. “Lives can be saved.”

email: [hdavis@buffnews.com](mailto:hdavis@buffnews.com)

The Buffalo News works to promote civil conversation in the comments section below. Please review the user guidelines before commenting.

Having trouble posting a comment? Visit [The News’ commenting troubleshooting page](#).