

GUEST ESSAY

Tonya Ingram Feared the Organ Donation System Would Kill Her. It Did.

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It's 2019, and the 27-year-old poet and mental health activist Tonya Ingram is looking for a kidney on Instagram. Her best option is to compel someone to agree to a living donation. Where Tonya lives in California, the wait list for a kidney from a deceased donor is up to 10 years long. Tonya, like many on dialysis to treat kidney failure, knows the odds of her surviving the wait are slim; the median survival time for patients on dialysis is five years.

I first met Tonya after seeing her post on Instagram seeking a donor. At the time, I was a video producer for New York Times Opinion working on a story about the failures of the organ recovery system and how patients were resorting to do-it-yourself tactics to find organs in time to save their own lives. Tonya appeared in my video illustrating the problem. Everyday Americans are doing their part, signing up to be organ donors, but the organizations in charge of organ recovery (known as organ procurement organizations, or O.P.O.s) have been plagued with inefficiencies and abuses, and the contractor that runs the national system — the United Network of Organ Sharing (UNOS) — has been failing to oversee them.

The organ procurement system is made up of 56 organizations, each with a monopoly in its jurisdiction. When someone dies and can donate an organ, O.P.O.s are supposed to go to the hospital, talk to the person's family and manage the process of transporting donated organs to those in need, but all too often they have failed to show up — literally. The most recent government data from 2020 shows that most are either underperforming or failing, and some O.P.O.s have reported inaccurate data to cover it up. According to a study updated in 2019, O.P.O.s failed to recover around 28,000 organs a year, viable organs that could save some of the roughly 100,000 people waiting for them.

Tonya asked the government to hold these organizations accountable, and naïvely, we thought it would be that simple. Our efforts would surely get Tonya a kidney.

She did everything she could to advocate for change, everything that our government asks of concerned citizens: She wrote an op-ed; appeared in a government video; wrote letters to members of the Biden administration, including the Centers for Medicare and Medicaid Services (CMS) administrator Chiquita Brooks-LaSure and the head of the Health Resources and Services Administration, Carole Johnson; worked with her local congresspeople, including Representative Katie Porter; and even testified before the House Oversight Subcommittee on Economic and Consumer Policy in May of 2021.

That day, she told the committee she would die without the federal government's urgent action. A year and a half later, on Dec. 30, 2022, Tonya died of complications from kidney failure.

Tonya's death wasn't caused only by a failure of her kidneys but also by a gross failure of our government and its lack of urgency and effectiveness. In politics, this problem has all the makings of an easy one to fix: The solution already has bipartisan support and would be both cost-saving *and* lifesaving. CMS has projected that holding these government contractors accountable would save more than 7,000 lives a year — translating to \$1 billion saved in foregone dialysis. If the 28,000 organs that go to waste each year were recovered and transplanted, the wait for livers and lungs could disappear altogether within just two years.

We also know that the solution we called for back in 2019 — government oversight — actually works. After Senator Todd Young of Indiana started calling into question his home state O.P.O.'s potential misuse of Medicare funds in 2019, improvements were almost immediate. In what seemed to be a response, the O.P.O. reported a 57 percent increase in potential donors approached, and a 44 percent increase in actual donors in just one year.

Following the video Tonya and I made, in 2020, the Trump administration finalized a rule bringing accountability to the forefront, and the Biden administration has inherited it. This is a good start: The new rule changes the metrics by which O.P.O.s are evaluated and would require them to face decertification for failure to perform. But the rule does not replace a single failing organ contractor until 2026, which is not acceptable. As the former head of the N.A.A.C.P. Ben Jealous has written about the delays, “If we understand the problem and know the solution, to withhold its implementation is cruel and senseless.”

To make matters worse, in the Biden administration’s 2023 budget, CMS requested flexibility to recertify failing O.P.O.s so they can keep their contracts even after 2026. If we allow failing O.P.O.s to keep operating, then we essentially nullify the reform we’ve worked so hard for, and ensure further delays and more deaths.

When you are on the wait list for an organ, time is of the essence. I know this firsthand. When I needed a liver transplant in 2004 at the age of 11, my doctors were worried I wouldn’t get one in time, so they encouraged me to travel to another state with a better-performing organ procurement organization. This is common. Many patients are told to travel to see if they can get an organ in an area with a shorter wait list. Thankfully, my dad was willing and able to be a living donor, so I didn’t have to rely on the wait list in my state or need to travel. But we can’t have a system that relies on individuals’ time, money and resources.

LaQuayia Goldring, 33, who testified alongside Tonya before the House Oversight Subcommittee on Economic and Consumer Policy in 2021, posted an urgent plea on social media for a kidney donor to save her life on Jan. 18. She’s been on dialysis for seven years. If a person has to circumnavigate the government system by appealing to the generosity of strangers, the system isn’t working. We need a fast fix for LaQuayia and the others whose lives are needlessly at risk.

Senators Ted Kennedy and Bill Frist first highlighted this problem in 1996, and in 1999 Forbes referred to UNOS as a “cartel.” When the Senate Finance Committee finally began investigating, it found that UNOS is systematically failing to provide oversight. At the committee hearing, doctors and transplant professionals testified that they have been afraid to criticize UNOS publicly, for fear it will retaliate against their patients. Also at the hearing, Senators Elizabeth Warren, Charles Grassley and Rob Portman called out another mind-boggling fact: From 2014 to 2019, UNOS was 15 times more likely to lose or damage an organ in transit than an airline is a passenger’s luggage.

Why is it taking so long for anything to actually change? The question haunted me before Tonya’s death, when I thought I could help save her life, and it’s haunted me only more ever since she died.

I watch Congress and the Biden administration barter, bicker and politic on issues with far less urgency and import. Sometimes I wonder if the problem doesn’t get solved because so many of the heroic advocates who square off against executives and their lobbyists have disappeared in sickness or in death.

As someone born into illness, I’ve seen many of my young, sick friends die. It’s always horrible, but Tonya’s death was preventable. She was the victim of a broken system, a system she tried so hard to change. Before too many others follow, Congress needs to hold the Biden administration to the bipartisan recommendations of the Senate Finance Committee: publish critical data, break up the national organ monopoly and replace the O.P.O.s whose failures hold patients’ lives hostage.

Tonya did her part. Now it’s on the Biden administration to finish the job.

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