

January 31st, 2022

The Honorable Chiquita Brooks-LaSure
Administrator, Centers for Medicare and Medicaid Services
200 Independence Ave., SW
Washington, DC 20201

Submission for RFI on Organ Procurement Organizations

Dear Administrator Brooks-LaSure,

My name is Tonya Ingram. I am a poet, Cincinnati native, Bronx-bred introvert, Los Angeles resident, mental health advocate, cat auntie, Tom Hardy lover, and “The Office” fanatic, and I need a kidney transplant.

In response to this Request for Information, I am sharing with the Biden administration what I shared with the House Oversight Committee, testifying at its [hearing](#) into the failures of organ procurement organizations (OPOs) in May 2021.

I was diagnosed with lupus at 22 years old, and as a result of that, in October 2018, I was diagnosed with end-stage kidney failure. My entire world collapsed. Since then, I have lived on dialysis just waiting to receive this new form of life. My health is my job. That is my main, primary focus.

I have to be aware of the energy I have. I have to take all these medications. I am exhausted most days. I started telling my story because I have to take my health into my own hands. I have to be my own advocate. I just knew that I would get more out of Instagram than from the actual healthcare system. Last night, I hooked myself up to a dialysis machine at 9 o'clock at night for the eight hours it would take for a machine to clean my blood.

At the age of 30, that's a lot to deal with, and I still have to wait for an organ to be able to have a second chance at living a healthy and long life. It is a very exhausting process waiting for a transplant. Because of my rare blood type, being on the list could mean that I have to wait 10 years before I can receive a transplant. Ten years is a very long time for anyone. I can't even think 10 years into the future right now, and to know that I won't have a kidney until then is a very daunting and heavy thing. I know I'm not unique in that sense. That just is what it is. It's waiting.

It's hard to know that I'm waiting for life. I'm waiting to live. And I'm standing alongside more than 100,000 Americans, most of whom are waiting for kidneys, though others need hearts, lungs, livers, and other organs. Imagine reading about a broken system when you are still waiting, to read investigative reporting about literally hundreds of organs going mishandled and lost in transit. Every one of those organs is a shot at life, and yet they're being treated like old luggage. As I've learned, this is just one problem in a horribly broken organ donation system. To learn that 28,000 organs go transplanted every year, including more than 17,000 kidneys, almost 8,000 livers, 1,500 hearts, and 1,500 lungs, that is unconscionable.

The organ procurement organization that serves Los Angeles where I live is failing, according to the Federal Government. In fact, it's one of the worst in the country. One analysis showed it only recovered 31 percent of potential organ donors. Audits in previous years found that L.A.'s OPO has misspent taxpayer dollars on retreats to five-star hotels and Rose Bowl tickets. The CEO makes more than \$900,000. Even still, the L.A. OPO has not lost its government contract, and it has five more years to go.

And so I wait. And I hope—I hope that it doesn't always have to be like this. Sometimes when you're in this diagnosis, it kind of feels like this is it and I will just be waiting forever until I'm no longer here, but I think this is the reform that will bring true hope. Reforms mean I will get this kidney; I will get this new chance at my life continuing, knowing that the chapter doesn't have to end here and there is this whole other story that I get to engage with. My dream is to have a healthy body, a working kidney, and a life that is mine.

As I testified in front of Congress, and as I write now to the Biden administration, please remember that I am a person with a story before kidney failure, and I'll have a life after kidney failure.

Every other patient on the organ waiting list has their own story, their own life to live, if the system will let them. We have so much to live for, and that's why we're fighting for this opportunity to do that—to live. Please don't make us wait. Too many Americans are dying unnecessarily due to basic failures of OPOs.

Accountability is urgent, and the consequences could not be more dire. Knowing which OPOs are failing - and how many patients are dying - makes it unconscionable to wait until 2026 to replace failing contractors with competent ones. As [Ben Jealous](#), past president of the NAACP, wrote urging CMS to accelerate the OPO rule: *"If we understand the problem and know the solution, to withhold its implementation is cruel and senseless."*

The very least the federal government can do is commit to transparency in this field where too many have died due to OPO failures and protectionism. The Centers for Medicare and Medicaid Services should:

- **Accelerate accountability:** replace failing OPOs with higher performers based on data available now as waiting until 2026 will consign tens of thousands of Americans to death, and disproportionately hurt patients of color; the only thing that should matter to CMS now or in future contracting cycles for competition is data showing evidence of more lives saved and equitable service for the whole community, CMS' preference for incumbency of OPO is killing patients;
- **Be transparent:** directly communicate OPO data and failures in understandable formats to the public, OPO board members, and Congress so that OPO performance can no longer be shrouded in secrecy;
- **Ensure equity:** collect and releasing OPO process data, in line with well established best practices for international OPO transparency standards, so the public can have evidence of equitable treatment and understand where organs are going missed (e.g., does my OPO have the same response rates and response times for patients of color as white patients? for patients in rural hospitals versus urban ones?)

- **Prohibit conflicts of interest:** failing CEOs are earning [\\$1,000,000+ taxpayer funded salaries](#), and board members of these nonprofits are earning up to [\\$100,000](#) a year, too - completely divorced from their performance; even so, executives and CEOs alike can currently engage in financial arrangements with for profit tissue companies without the public knowing; this has to stop.
- **Bring oversight back to the federal government:** patients die while various government agencies and contractors hold no one accountable (see the fact that no OPO has ever been decertified, despite [criminality](#), [misspent taxpayer dollars](#), and [patients deaths due to basic errors](#)); UNOS has failed in its most basic responsibilities as the nation's organ procurement transplantation network (OPTN) contractor, proving the federal government needs to be accountable for oversight, rather than offloading it to conflicted contractors.
- **Replace UNOS:** not only has UNOS failed at oversight (see the [bipartisan investigation](#)), it operates "[antiquated technology](#)" - leading organs lost in transit and organs being offered to dead people, all while patients languish on the organ waiting list; the Department of Health and Human Services (HHS) needs to replace UNOS through a first-ever competitive contracting process; [once again, HHS' preference for incumbency is killing patients](#); and
- **Support any reforms coming out of the bipartisan House Oversight and Senate Finance investigation:** the [Senate Finance Committee](#) and the [House Oversight](#) have shown that mismanagement of organ donation contractors is killing Americans. [Republicans and Democrats](#) are working together to support patients, and the HHS should act on any findings and reforms.

More than 100,000 Americans are currently on the waiting list for an organ transplant. Too many will die waiting. Please act like our lives depend on it, because they do.

Yours sincerely,
 Tonya Ingram
 North Hollywood, California