Testimony of LaQuayia Goldring Kidney Transplant Recipient and Kidney Transplant Candidate The Senate Committee on Finance Health Care Subcommittee Hearing on "The Cost of Inaction and Urgent Need to Reform the U.S. Transplant System" Thursday July 20, 2023

Hello and good morning Chairman Cardin, Ranking Member Young, and Members. Thank you for this opportunity to testify before you today.

My name is LaQuayia Goldring, and I am currently dependent on the U.S. organ donation system to save my life while I await the lifesaving blessing of receiving a 2nd kidney transplant — and the system is badly failing me.

As a toddler at the age of 3 I was diagnosed with a rare kidney cancer called Wilms tumor (a golf ball size tumor) took my left kidney; Due to that at the age of 17, when I was diagnosed with stage five kidney failure, I was placed on the UNOS waiting list and received my 1st kidney transplant.

At the age of 25 I went back into complete kidney failure. I've now been waiting nine long agonizing years for a transplant, dependent upon a dialysis machine 5 days a week to live. I was told I should receive a kidney transplant within 3-5 years and still I wait as I continue to undergo monthly surgeries on my dialysis access to get adequate treatment. The UNOS Waitlist isn't like 1-100, I am never notified of where I stand on the list because an algorithm is meant to determine my fate. Every day that I'm waiting, I'm closer to becoming one of the 30 Americans who die each day waiting for an organ transplant.

I know this all-too-well, and that's why I've had to turn to social media to try to find a living donor. I've lost multiple friends and family to organ failure. I've seen more funerals than success stories. I don't want to be next.

The reason it's so hard for me to get a transplant is because the government contractors running the organ donation system are failing and corrupt.

I grew up in rural Kentucky, where the organ procurement organization, or OPO — like more than half of OPOs across the country — is failing. OPOs fail to recover as many as 28,000 lifesaving organs every year. And even when they do recover organs, they waste them. More than 1 in 4 kidneys are thrown in the trash after a generous family has donated them.

It's even worse for minority labeled patients. Our Kidney function was wrongly calculated by UNOS race based calculations, delaying our access to transplant. OPOs are less likely to respond to potential donation cases if the donor patient is of Black/Brown descent, and they treat those of us with less urgency, care and compassion. I know this firsthand as my grandmother was a donor and we had to reach out for our OPO just to show up.

These failures lie at the feet of the monopoly contractor in charge of managing the U.S. organ donation system — UNOS.

Patients like me are completely forgotten by the system. Just a few weeks ago, a donor's family wanted to make a directed kidney donation to me, meaning that they chose for me to receive their loved one's kidney.

This should have been my second chance at life, but my name was unable to be found at first as active on the UNOS transplant waitlist, but I was told that this was a "clerical error", and that I should have been listed as "active."

This wasn't a one-off event. UNOS's technology is insecure and unreliable. It crashes regularly for hours at a time, meaning patients like me can't get organs, and kidneys are regularly lost at airports and thrown in the trash. Every time this happens, patients like me die. You can't even imagine how that feels.

In UNOS's system, Black patients are three times more likely to need kidney transplants than white patients, but less likely to get them. The inequity isn't an accident. It's by design.

An email from an OPO CEO, who at the time was a UNOS board member, justified a policy proposal that would systematically hurt minorities based on where we live by saying that we are "dumb [expletives]" for living in the South and rural America in the first place.

What they think I'm too dumb to realize is that they've rigged the game for themselves. OPOs waste taxpayer money on 7-figure salaries, private planes, golf tournaments, and retreats to wine country. The whole system is set up to make a few people rich. They get beach houses; patients get coffins, especially patients who look like me.

But there is never any consequence for them because the government has never held them accountable. The government has failed me. The only solution is to replace failing OPOs and to get rid of UNOS.

This is urgent. We need to break up the UNOS monopoly now. Not in two to four years, but now. Not tomorrow, but today. I am grateful for this Committee for introducing legislation to do exactly that, and I hope you will do everything you can to ensure that it passes. Lives are at stake.

In 2021, I testified before the House Oversight Committee alongside another patient, Tonya Ingram. She urged the government to hold OPOs accountable, warning that she would die if they did not. Her calls were ignored, and Tonya passed away last December. She deserved better, as do patients across the country.

Please help give us a different fate. Thank you.