Dara Kass Testimony May 4, 2021

Subcommittee on Economic and Consumer Policy Remote Hearing on “The Urgent Need to Reform the Organ Transplantation System to Secure More Organs for Waiting, Ailing, and Dying Patients.”

Sammy Kass is our youngest son. He was born smaller than our other children, at just over 5 pounds.

Baby’s lose weight right after they are born, and most gain it back in the first couple of weeks. When they don’t, we start to look for clues that something might be wrong.

When Sammy was 8 weeks old, we found out he had a condition called alpha-1 antitrypsin deficiency. This is a recessively inherited disorder that neither my husband or I knew we carried. Being a doctor, and his mom, I was devastated.

His disease was causing liver damage, which was, in turn, preventing Sammy from gaining weight. We spent the next few months seeing doctors, supporting his needs and watching him closely, aware that a small percentage of babies with this type of liver damage will not get better, but get worse, and that he might need a liver transplant.

One afternoon, just shy of Sammy’s 1st birthday, we had to take him to the emergency department because he had a fever. We needed to make sure he didn’t have an infection in his belly near his liver. After the workup his doctor pulled me aside and said, “Today things are going to be ok, but he is headed for a transplant.” He then asked if I would consider being his living liver donor.

At that moment, after nearly a dozen years of being a doctor, and a few less as a mom, images raced through my mind.

I saw patients getting sicker waiting for a new organ and their entire families exhausted knowing the call could come at any time, like the middle of any night - or maybe never at all.

I remembered all the delays and frustrations I had communicating with the organizations responsible for this process and I knew, instantly, that I could bypass the entire system by becoming a living donor and save my son’s life. In that moment, the overwhelming fear that Sammy would never receive a new liver went away.

Living donation is a privilege and it is not without its risks and complications. The socio economic burdens of living donation like unpaid time off work, multiple members of one family becoming patients and the inability of the donor to serve as the primary care provider for the transplant patient, mean that families without support or resources may not be able to pursue this route, even if it is medically possible.

And living donation, of course, is also not possible for all patients, like those who need a heart or lungs. It was a saving grace for our family, but by no means should it be thought of as the scalable solution.

The backbone of organ transplantation in America is deceased donation, which is managed by a network of organ procurement organizations (or OPOs). We cannot overstate the urgency upon us in reforming the OPO system to ensure that it is functioning and accountable.

As an ER doctor, I had repeatedly witnessed OPOs mismanage families, communicate poorly, and ultimately leave organ transplant patients languishing on the waiting list.

OPO treatment of communities of color has been deeply substandard, leading to worse outcomes for Black and brown patients needing transplants, as well.

And never - not once - has a single OPO in the country lost its government contract, despite these deep breaches of public trust.

While my family's transplant experience reinforced my understanding of the need to support OPO reform, living through the last year of the COVID pandemic has accelerated the urgency for the system to work for all patients.

While we've lost over half a million Americans to COVID, millions more, who have recovered, will have long-term health effects from their infection. Acute COVID infection sets off an inflammatory response that can damage your lungs, your heart, your liver, or your kidneys.

Communities of color have been decimated by this pandemic, and the fact that COVID infection can cause organ failure requiring a transplant means that Black and brown patients, who were already hardest hit by their acute COVID infection, will be further harmed by the broken organ procurement system and the patients it hurts the most.

You don't have to take my word for it. As Chairman Krishnamoorthi and Representative Porter wrote in February,

"We must move urgently to implement OPO reforms today to serve COVID-19 survivors tomorrow."

In conclusion, I will reiterate that my family is one of the lucky ones. Even in the face of a devastating diagnosis and a life altering path for our child, we knew we were in a position of privilege. And now, almost 7 years after my son and I were able to split one "chopped liver", we are here to fight for those who still need their chance.