

House Committee on Oversight and Reform

Subcommittee on Economic and Consumer Policy

**“The Urgent Need to Reform the Organ Transplantation System to Secure More
Organs for Waiting, Ailing, and Dying Patients”**

Tuesday, May 4, 2021

Testimony

Donna R. Cryer, JD

Liver Transplant Recipient

President & CEO, Global Liver Institute

Good morning. My name is Donna Cryer and I am the President and CEO of Global Liver Institute. We are the only patient-driven, nonpartisan liver health nonprofit operating in the United States and Europe.

Thank you, Mr. Chairman, Mr. Ranking Member, and subcommittee members for your bipartisan support and commitment to solutions to save the lives of the more than 107,000 Americans who are in need of an organ transplant right now.

I was once one of those people. Because of an autoimmune disease that was diagnosed when I was in 8th grade, my entire digestive tract has been affected. Shortly after I graduated from Harvard I was told that I had so little liver function left that I would not survive two years without a liver transplant. I had my colon removed as the cells became cancerous, my doctors recognizing that my body could not defeat cancer once I was immunosuppressed. Over the course of four months I experienced multi-organ failure, lost clotting factors, bleeding out repeatedly, and spent time in both medical and surgical intensive care. Ultimately, my parents - both school teachers, my mom at my bedside every day, my dad looking after my little brother at home - were told that I only had seven days to live.

Fortunately, an organ was donated and recovered in those seven days.

For [33](#) patients today and every day, that will not be the case. They will die while waiting for an organ. Professional football player Geno Hayes died last week while waiting for a liver donation. He was 33 years old. His loss reminds us that fame, money, or status can never substitute for a system that works efficiently to connect patients with precious life-saving organs.

In fact, if we act today, and start holding OPOs fully accountable, there would not need to be a liver transplant waiting list at all.

Everything that I have accomplished since my transplant - graduating law school at Georgetown, getting married, building a family, every job that I have created, every patient that I have counseled or mentored, every community in the U.S. and around the world that I have served - is in honor of the generous gift of life from someone and an organ procurement organization (OPO) that ensured that gift led to my transplant. I would hope that everyone here today is focused on ensuring that every patient and family waiting has the same opportunity for a full and healthy life.

Across more than twenty years of personal and professional experience as part of the transplant community, as a patient, UNOS patient affairs specialist, and a member of the UNOS Membership and Professional Standards committee; on the boards of a hospital, research network, and several other nonprofit health organizations, my assessment is as follows:

Many conditions cause organ failure. For example, the nearly 12,000 patients waiting for a new liver are there due to multiple causes including Covid-19 and other viruses, pediatric genetic diseases, autoimmune conditions, toxins (such as accidentally ingesting too much acetaminophen), and fatty liver disease, in its most severe form called NASH.

Our system for organ procurement does not need to continue to fail patients.

Since the organ transplant system relies on organ recovery, the bipartisan rule that will finally hold OPOs accountable is critical. And given that [COVID-19 damages organs](#), we should not delay accountability for one more day.

This is not just my recommendation. Together patient advocacy organizations like Global Liver Institute, the National Kidney Foundation, the American Association of Kidney Patients, Organize, and medical societies like the American Society for Nephrology worked productively with HHS under both the previous and current administrations to enact greater measures for transparency, accountability and equity in the organ donation, recovery, and transplantation system.

As Matt Wadsworth, CEO of Life Connection of Ohio, wrote: the OPO rule has “been advocated for by as diverse an expert group as any public health initiative in recent memory.” These voices have included: “the organ donation leads for both the [past two White Houses](#); a [Nobel Prize winning economist](#); the former [Chief Data Scientist of the United States](#) under President Obama; policy leaders varying from the former [Acting Administrator of the Centers for Medicare and Medicaid Services for President Obama](#)

to the [Executive Director of the Senate Conservatives Fund](#); leading national philanthropies including [Schmidt Futures](#) and [Arnold Ventures](#); all five (bipartisan) former [Chief Technology Officers of the US Department of Health and Human Services](#); the former [President of the NAACP](#); and a [broad, bipartisan swath of Congressional representatives](#)".

Specifically, this diverse but united community has asked for an organ procurement system that can produce thousands of additional life-saving organs for transplant, based on:

- 1) Transparency - Patients and the American people deserve accurate, reliable, publicly available data rather than self-reported, made-up grades submitted by government contractors themselves, which the [former US Chief Data Scientist](#) said are "functionally useless".
- 2) Accountability - There have not been any consequences for failing OPOs, no matter how egregious the offense or how poor the performance. Meaningful enforcement has to mean that there is some universe where people are at least at risk of losing their jobs because too many people lose their lives. There are many highly qualified leaders ready, willing, and able to take on this important public charge.
- 3) Equity - Equity matters, ethically, scientifically and by law. People of color are [1.5 - 4 times](#) more likely to have conditions leading to kidney and liver failure but less likely to receive transplants. Organ transplant matching and survival are based in part on blood types, antigen matching, and other factors enhanced by a diverse donor pool and chance for a closer genetic match. Failure to invest resources in adequate community outreach activities including for limited English proficiency, in the languages spoken by their community members, and hiring diverse staff to have these most difficult conversations with families result in unnecessarily low awareness and trust levels. Multiple surveys and research studies have shown that OPO staff are [less likely to approach families of color](#) for consent, have [less frequent conversations](#), [spend less time in those conversations](#), and [demonstrate bias in assumptions](#) of who would be eligible or willing to donate. My family's experience is an example. Despite my father's death in a hospital from a car accident, with all the right decisions by my family with his doctors to keep his organs viable, his organs were not recovered. Because of my successful transplant, We brought in our whole family and our pastor to communicate the decision to donate, and to be told perfunctorily that not one organ or tissue would be used was devastating.

Why does the organ transplant system work for some patients -- as in my case -- and not others -- as in my father's case? OPOs' poor performance in too many instances plays a part.. That variability is deadly. Years of uncorrected poor performance by OPOs have created inequities because some patients, recognizing their low chance of getting a deceased donor organ where they live, travel and list at multiple centers. Most people can't afford to do this. Some

patients are able to use vast social networks and media savvy to recruit their own donors for living donor transplants. Basically patients feel they have to do the work of the OPO because they can't rely on the organizations paid to find organs.

All of these issues are unacceptable and unnecessary. We know what works. The best practices of high-performing OPOs are [documented and shared](#). We should not be satisfied until every OPO is performing at the level of the highest performers and realizing the full donor potential of their service areas. We should not be satisfied until we can assure the public that [taxpayer dollars are appropriately invested](#) in education, innovation, and technology that result in more lives saved. We should not be satisfied until every family in every zip code, of every race and socioeconomic status, is aware of and approached for donation in a timely and compassionate way. We should not be satisfied until the number of patients waiting for an organ is zero.

The OPO final rule is a critical first step toward reducing waiting lists that are much longer than necessary. But as no OPO will currently face decertification until 2026, I ask the Committee to do all that it can to usher in urgent accountability sooner. COVID-19 - and its devastating, inequitable effects - will only make things worse, creating more patients with organ failure. We can't wait.

Remember, this is about saving lives. Currently waiting in your home states are:

- 3,888 people in Illinois
- 9,899 people in Texas
- 21,146 people in California
- 1,668 people in Missouri
- 4,218 people in Georgia
- 4,621 people in Massachusetts
- 6,817 people in Pennsylvania
- 4,962 people in Florida

On behalf of these patients - your constituents; all those waiting; on behalf of donor families who hope to give life out of death, and myself, we thank you.

I look forward to your questions.