



**Donna Cryer, JD, Founder and CEO of the Global Liver Institute  
Witness Testimony: Liver Transplant Recipient  
United States Senate Finance Committee, Health Subcommittee  
July 20, 2023**

Thank you, Mr. Chairman, Mr. Ranking Member, and committee members for your bipartisan support and commitment to save the lives of the more than 100,000 Americans waiting today for a solid-organ transplant by passing legislation to break up the deadly federal organ donation monopoly and insisting that HHS steps fully up to its Congressionally-authorized role to protect donors and patients relying on the transplant system.

My name is Donna Cryer and I am the President and CEO of Global Liver Institute, the only patient-driven, nonpartisan liver health nonprofit operating established in the United States and operating through partnerships with more than 55 countries and 200 medical societies, patient advocacy organizations, and other health promoting organizations through our Councils, campaigns and events.

I have worked in the organ donation field for almost three decades, since my own life-saving liver transplant from a rare autoimmune disease and have seen these issues from all angles: as a Harvard and Georgetown educated lawyer; a non-profit consultant, executive and founder; as a GAO appointee to the HIT policy committee, a SGE representative to the U.S. Food & Drug Administration; and the first call that thousands of patients and families who find themselves in the overwhelming circumstances of donating or waiting for the precious gift of life have made.

As far back as 1993, when I navigated the circuitous route to be diagnosed in liver failure, and evaluated for a transplant, the gaps, inequities, and burdens on families posed by what is called our transplant “system” were apparent. The decision to dedicate my gift of life to helping other transplant patients by finding ways to improve the system was clear. I started my career by serving in various roles for the United Network for Organ Sharing, UNOS, the federal organ transplant monopoly contractor, which this very committee is investigating.

I have waited decades to give this testimony. Only by the grace of God am I alive to give it. The failures of the U.S. organ procurement system are devastating, leaving in their wake needless death and breathtaking inequity. The fault lies squarely with UNOS, as well as many of the nation’s organ procurement organizations, or OPOs, which UNOS is supposed to oversee, under government contract.

At every turn, the organ industry is seen to prioritize executives over patients. But, perversely, because organ donation is such a beautiful gift on behalf of generous donor families, and the science enabling it is such a marvel, the public has been blind to the hard truth that the industry behind it is corrupt.

I hope today that we are able to give you and everyday American citizens a chance to see behind the curtain.

My first role with UNOS was as a Patient Affairs Specialist which gave me views into policy, education, and communications. I sat in on staff leadership meetings, negotiation strategy sessions for dealings with HRSA, and it was even my job to draft the Board minutes. Years later I was elected as a member of UNOS's Membership and Professional Standards Committee, or MPSC, which is charged with reviewing patient safety lapses and generating remediation plans. I hoped that would provide a different vantage point for me to make a difference.

The Senate Finance Committee's investigation findings revealed UNOS executives joking that the MPSC is *"like putting your kids' artwork up at home. You value it because of how it was created rather than whether it's well done", are consistent with my first-hand experiences.*

The joke, I guess, is that UNOS knowingly leaves patients unsafe and unprotected. I fail to see the humor in it.

What I experienced first-hand was that MPSC decisions were made by a small cabal of industry insiders protecting each other, routinely ignoring or excusing abhorrent and dangerous behaviors.

The patient in me was traumatized. The lawyer in me wondered at what point the HHS staff in the room who were supposed to oversee the overseers would step in and act. UNOS has been well-aware, for decades, of severe and often fatal risks to patients, and has worked far harder to cover them up than to fix them.

There is no reason to believe that UNOS has changed since then. Many of the same executives are not only still there, but have been promoted, for example the current CEO, Maureen McBride, who has been there since 1995.

UNOS executives know as well as I do that patients are dying needlessly in every stage of the system, yet I am not aware of a single meaningful action they have taken to address this. They post pretty words and press releases on their website pledging to do things that they have been empowered and requested to do for decades.

This time can be different. I have come before you to ask specifically for the Senate passage S. 1668, Securing the U.S. Organ Procurement and Transplantation Network Act, and to continue to keep the spotlight on the Centers for Medicare and Medicaid Services' (CMS) responsibilities in transplantation. CMS needs to, without further delay, use data that they do have to enforce

regulations to hold organ procurement organizations (OPOs), the government contractors in charge of reaching out to donor families and securing donor organs, accountable for their performance, and to do so without caving to industry lobbying pressure to weaken these standards in any way.

With rare exceptions — which only demonstrate how good leadership and high performance are possible and in fact transformative to a region — a majority of OPOs are not only failing across multiple measures of performance, but have specifically been shown to systemically deprioritize outreach to Black and Brown families and communities, leading to fewer transplants to Black and Brown patients.

CMS taking the long-awaited actions requested by communities, patient, and donor family advocates across the country would make organ procurement safer, more equitable, and elevate the quality of organs available. Transplantation is often painted as complex, but a few simple steps would make a significant difference. Here are some examples: Openly publish OPO process data. Require that all staff interacting with patients have some baseline clinical training or licensure. Require adverse patient events to be reported publicly.

Innovation and reform will never come from the same people who are perpetuating the current dire status quo. Industry will push back, as it always does, with protectionist arguments that any change is disruptive, but I will assure you that nothing is more disruptive than dying. At my sickest point, doctors stood outside the ICU and told my mother that I only had seven days left to live. Right now, under the current regime, 210 people are estimated to die in the next seven days. They will not be saved by empty promises that reforms will come years down the line. They need you, Senators, to act today.

Thank you.