

WRITTEN TESTIMONY OF  
**BARRY S. FRIEDMAN, RN, BSN**  
EXECUTIVE DIRECTOR  
ADVENTHEALTH TRANSPLANT INSTITUTE  
BEFORE THE  
**SENATE FINANCE COMMITTEE**  
**AUGUST 2, 2022**

Chairman Wyden, Ranking Member Crapo, Senator Grassley, and Members of the Committee:

On behalf of AdventHealth, I am honored to be extended the opportunity to provide testimony on the current state of organ transplant policy in the United States. My testimony reflects more than 30 years of health care/transplant experience and my direct leadership involvement in The United Network for Organ Sharing (UNOS) and the Organ Procurement Transplant Network (OPTN), including the UNOS board of directors and the Membership Professional Standards Committee. I also proudly served 30 years in the United States Air Force—including two tours of duty during *Operation Iraqi Freedom*.

I currently serve as the Executive Director for the AdventHealth Transplant Institute, one of the busiest transplant centers in the nation, having performed more than 4,000 transplants. Our survival rates are among the highest in the country, making us one of the most highly-sought adult and pediatric multi-organ transplant programs in the United States. We were the first hospital in Central Florida to successfully perform a heart transplant. Today, we offer a wide range of transplant options, including, heart, kidney, lung, liver, pancreas, and blood and marrow. We are also home to a comprehensive living donor kidney program.

As the Executive Director of the Institute, I take very seriously our sacred duty to the families and patients who entrust us with the gift of life to provide organs for transplant. It is our duty to be good stewards of these organs, honoring the faith of these families and the health of our communities. I offer testimony specifically on UNOS/OPTN oversight of transplant policy, data and interoperability challenges, and opportunities to improve transplant equity across the nation.

**UNOS' Oversight of Transplant Policy**

Families in need of a lifesaving organ have no option but to trust the organ transplantation system that is in place. Unfortunately, that system has failed many awaiting organ transplant due to lack of oversight and accountability. An organ is the greatest gift someone can give and yet, we have created a system that does not result in the good stewardship of that gift. Approximately

23 percent of kidneys procured from deceased donors are not used and discarded, resulting in preventable deaths.<sup>1</sup> It is our responsibility to address this issue.

### *Avoidable Organ Loss*

**Organ transportation is a process left to each federally-designated Organ Procurement Organization (OPO) to implement.** OPOs currently develop their own relationships with transportation couriers, relying on them to engage with airlines, charter flights, ground transportation and federal agencies to facilitate transportation. If an organ leaves the OPO's custody, OPOs and transplant centers are solely dependent on airline personnel to move organs on and off commercial flights in an expedited manner. In many cases, organs must connect from one flight to another, leaving airline personnel responsible for transfers. Neither OPOs nor couriers have control of an organ upon surrendering it to the airlines. While anyone can now track where their Amazon or FedEx package is, there is currently no consistent way of tracking organs.

The OPTN recently broadened kidney-sharing policies with the goal of increasing the number of organs available. However, this policy is being instituted in an environment where the kidneys may be unescorted and unprotected during transit, making them more vulnerable to discard. This problem has been exacerbated due to industry staffing shortages caused by the pandemic and flight delays. There are occasions when we try to put the organs on charter flights, however, there are not enough charter flights available and the costs are significantly higher. When the transplant community raised these issues to UNOS at the regional meetings, UNOS staff stated that UNOS was not responsible for providing this service and that it was "out of scope for discussion."

Many news articles have promoted the use of GPS tracking during organ shipments.<sup>2,3,4</sup> UNOS developed an organ-tracking system to pilot with OPOs and transplant centers. However, staff from the UNOS Organ Center did not participate in organ tracking. There were no built-in warnings when an anticipated check point was not met. Further, the system depended on recycling the GPS trackers for repeated use, which was difficult if not impossible to do. Due to these challenges, we opted out of the UNOS tracking system and are now working with a

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<sup>1</sup> [How to Decrease the Discard Rate of Donated Organs](#), The American Society of Nephrology

<sup>2</sup> [For All Transplant Programs: The UNOS Organ Tracking Beta Test](#). UNOS, 2021.

<sup>3</sup> [How BrickHouse Security's GPS Tracking Helps the National Kidney Registry Save Lives](#). Fierce Healthcare, 2010.

<sup>4</sup> [How Lifesaving Organs for Transplant Go Missing In Transit](#). Kaiser Health News, 2020.

different courier company that uses less expensive and higher quality trackers which can be discarded and monitor shipments in real time.

*To address these organ transportation issues, this committee should recommend the following:*

1. Promote increased transparency by requiring the reporting of all organ loss and “near misses” due to transportation issues. UNOS has a safety reporting system, however, our program has reported these near misses with no feedback or follow up to the safety report submission.
2. Establish a national organ shipping system that would monitor the progress of all shipments (e.g., aircrafts, ground transport, train transportation) in real time on behalf of OPOs and transplant centers that opt in. This could be done through a partnership with a third-party organization that actually has expertise in this.
3. Require all OPOs to utilize GPS technology to transport unaccompanied organs. GPS tracking should be constantly monitored by either OPO staff or a contracted service.
4. Require the development of safety standards for courier and airline companies to follow when transporting human organs for transplant.

#### *Inferior Data Availability and Interoperability*

**Data availability and transparency are key to improving organ procurement, UNOS has not proven capable of this function.** OPTN technology lags significantly behind other technology platforms. In daily use by our transplant center, we have found the current OPTN IT contractor to be slow and reactive, one that does not provide state-of-the-art service and does not prioritize being technologically current. This contributes to a fractured flow of health IT between OPOs, donor hospitals, transplant programs, and UNOS with significant data interoperability challenges. During regional meetings, this issue was raised and even though transplant centers voted for a resolution, UNOS called these concerns “sentiments,” and they were not given serious consideration.

I also believe there is a conflict of interest related to the management of IT functionalities by UNOS, as the IT tools that they offer transplant centers come with an additional cost despite these being essential for the safely management of organs.

*To help improve the availability and useability of data, Congress should:*

1. Separate the IT components of UNOS operations from the broader OPTN contract with HHS.

2. Authorize and require OPOs and the OPTN to participate in Health Information Exchanges.
3. No longer require OPOs to maintain additional, separate databases with donor information, instead allowing them to transfer donor information directly from hospital EHRs to the OPTN database.

### Ineffective Organ Screenings

**UNOS is not effectively screening organ offers so they can be quickly directed to transplant programs.** Rather, UNOS asks transplant centers to voluntarily opt out of certain organ offers via an organ offer filtering process. History has repeatedly demonstrated that transplant programs desire to be informed of every organ available, even if they would never transplant it. Thus, they have a poor track record of voluntarily filtering offers. As a result, OPOs must waste valuable time making organ offers to centers that will never accept them. Time wasted equates to prolonged cold ischemic time, which equates to lost transplant opportunities. It is a vicious cycle that disadvantages patients on the waiting list. Thus far, UNOS refuses to adopt a more “placement friendly” philosophy. Additionally, while UNOS is proposing to increase their patient registration fees, they are not offering any increase in value or improvements in their processes.

**Due to the limited expertise that UNOS has in the placement of organs, it would be best if they were no longer responsible for developing organ placement practices.** In the early years of UNOS, the placement of organs was stellar. If UNOS cannot perform this task, we recommend high-performing OPOs and transplant centers be partnered with technology and artificial intelligence experts using predictive models about organ utilization. Prioritizing organ offers to the centers most likely to use them will drive change in transplant center organ acceptance practices.

**The UNOS policymaking process lacks transparency.** Currently, OPTN board members concurrently serve as the board members of UNOS, which creates a conflict of interest that contributes to the lack of transparency. The board then further delineates with an executive board, where closed-session decisions are made and sent out to the transplant community for implementation. UNOS has formed many committees throughout the years to develop policy changes. However, these committees are formed in a vacuum; there is no call for nominations and no data shared with the transplant community to explain the rationale behind a given policy change. A perfect example of this is the recent organ allocation change of policy where a geography committee was formed; this policy resulted in the inequitable distribution of organs and higher kidney discard rates.

UNOS requires transplant centers to pay a registration fee for adding patients to the OPTN waitlist to receive an organ transplant. Since 2021, these fees have increased from \$926.00 to \$990.00 in 2022; UNOS has proposed to increase the registration fees to \$1,044.00 in 2023. These are additional costs that go into the Medicare cost report, costing the federal government more money, with little transparency as to why. Transplant center leaders in the past have not been given a reason for these increases.

**There is no representation from patient advocacy groups or experts in quality measurement and improvement.** The OPTN should be required to ensure that all populations, including ethnic minorities and persons with disabilities, are represented in the transplant policy development process. Finally, there should be representation of organizations, like the National Quality Forum, that have experience in quality measurement. Failure to make these changes will result in the continued development of inequitable policies and practices that do not result in measurable quality improvements.

Overall and most importantly in this equation we are jeopardizing the trust to our most precious resource — organ donors and their families and the recipients of those organs.

We applaud the Senate Finance Committee for listening and learning today and thank you for providing the United States of America the opportunity to maintain the stellar clinical care for our patients who require lifesaving organ transplants.

Sincerely,

A handwritten signature in blue ink, appearing to read "B. S. Friedman".

Barry S. Friedman, RN, BSN  
*Executive Director*  
*AdventHealth Transplant Institute*