What is United Network for Organ Sharing?

- United Network for Organ Sharing (UNOS) is the non-profit that manages the nation’s organ donation and transplant system - the Organ Procurement & Transplantation Network (OPTN) under contract with Health Resources & Services Administration (HRSA)
- The U.S. has a complex, lifesaving organ donation and transplant system

UNOS works to develop and maintain an equitable organ allocation system for waitlisted patients through:

- Data-driven policy
- Technology ("the match")
- Quality
Structure of the OPTN

• Created by the National Organ Transplant Act of 1984 (NOTA)
  - Mandated a non-profit contractor operate the OPTN with experience “in organ procurement and transplantation”

• The OPTN and UNOS share the same Board of Directors
  - Board includes patients, donor families, OPO and transplant hospital professionals, and others

• Contract is structured so that the community drives policy, not the contractor
  - UNOS does not make policies, only facilitates per the contract
  - OPTN Committees recommend policies and the Board approves them

• Committees include a Membership & Professional Standards Committee (MPSC), which governs membership criteria and monitors OPTN member compliance
The OPTN Contract

• OPTN Contract includes a variety of requirements, including but not limited to:
  
  - OPTN governance structure
  - Supporting the OPTN policy development process
  - Coordinating OPTN policy development and analytic needs with the Scientific Registry of Transplant Recipients (SRTR)
  - OPTN member compliance and performance monitoring, quality improvement, and sanctioning
  - OPTN electronic matching of donor organs to transplant candidates
  - Security and privacy requirements
  - Collecting official OPTN data to support the operations of the OPTN
  - Communicating with OPTN members, transplant professionals, transplant patients, living organ donors, donor families, the media, and the general public
  - Providing written updates and summaries on OPTN activity as required for reports to Congress and/or other official reports
UNOS is Committed to Reform

“UNOS supports HRSA’s plan to introduce additional reforms into the nation’s organ donation and transplantation system. We also stand united with HRSA in our shared goal to get as many donor organs as possible to patients in need while increasing accountability, transparency and oversight.”

“We welcome a competitive and open bidding process for the next OPTN contract to advance our efforts to save as many lives as possible, as equitably as possible . . . Numerous components of HRSA’s plan also align with our new action agenda, which is a list of specific proposals we outlined earlier this year aimed at driving improvement across the system.”
Transparency

• Develop and release three new dashboards for lawmakers, regulators, professionals and the general public to better understand system performance

• Expand the new public page on the OPTN website about MPSC performance improvement and compliance review activities to increase awareness

• The OPTN will issue timely patient safety and improvement communications gleaned from current case reviews to inform the public, help members avoid safety events, and comply with OPTN obligations
Accountability

• Work with CMS and HRSA to establish consistent protocols for escalating cases and conducting investigations on underperforming OPOs and transplant hospitals

• Seek authorization for the OPTN to collect or receive data on ICU deaths for patients under the age of 70, which would provide a more accurate monitoring of OPO performance

• Provide OPOs and transplant hospitals education to improve understanding of both OPTN performance metrics and CMS regulations
  - This would require working with CMS to provide accurate and coordinated information and would assist OPOs and transplant hospitals in understanding the full scope of OPTN policies and CMS regulations.
Equity

• Seek authorization for the OPTN to collect pre-waitlist data to identify barriers to equitable access and quantify the national disease burden

  - Data would include characteristics of patients with end-stage organ failure and those subsequently referred to transplant hospitals; characteristics to be collected include clinical characteristics, socio-economic information, and patient demographics
  - This data could assist in improving policies to increase equity for the broader end-stage organ failure population
Transportation

• Allow organs intended for transplant to fly in the cabin
  - Currently, organs on commercial flights are required to travel in cargo
• Support policies to require GPS trackers on all unaccompanied organs
• Advocate for the development of and an investment in a national organ tracking system
Governance

• UNOS first engaged with HRSA regarding separating the UNOS and OPTN Boards in 2021

• UNOS revisited the proposal in 2022, offering an amendment to the existing OPTN contract with HRSA to accomplish a fully compliant restructuring with separate boards of directors by the end of the current OPTN contract, on September 29, 2023.
  - Partnership with HRSA is essential to the successful development of any OPTN governance restructuring plan
What Can Congress Do?

• Engage with UNOS to host round tables with Hill staff to increase understanding of the transplant system, the distinct roles of UNOS, OPTN, CMS and HRSA to help as Congress works to improve the donation and transplant ecosystem

• Require CMS to review performance metrics for transplant hospitals, in coordination with the OPTN, for a more holistic view of system performance

• Require HRSA to authorize the OPTN to have access to pre-waitlist data to determine the national disease burden and identify barriers to access to the waitlist

• Require HRSA to coordinate with the OPTN Board to accomplish a governance restructuring, separating the UNOS and OPTN Boards

• Require that the next OPTN contract mandate the use of physical trackers for unaccompanied deceased donor organs recovered for transplant