Chairs Rogers and Griffith, and members of the committee, thank you for the opportunity to speak with you today. My name is Robert Cannon, and I'm surgical director of the liver transplant program at the University of Alabama at Birmingham. On my desk there is a handwritten note from a patient's family thanking me for saving their daughter's life with a liver transplant. I keep it there to remind me of the awesome privilege and responsibility I have as a transplant surgeon to serve patients in their time of greatest need. The true heroes in the story of transplantation are not physicians, however, but rather are the donors and families who give selflessly in what may be the darkest moment of their lives, the patients suffering from organ failure waiting for a phone call that may never come, and the thousands of organ donation and transplant professionals who bridge the gap between them. I'd like to speak with you today about a system that has let these heroes down.

A critical feature of the 1984 National Organ Transplant Act (NOTA) was the provision that the Organ Procurement and Transplantation Network (OPTN) was to be operated by a contractor tasked with overseeing and running the entire system. This contract was first awarded to the United Network for Organ Sharing (UNOS) in 1986 and been held by them ever since. The men and women of UNOS perform lifesaving work to facilitate the smooth operation of our transplant system. Another key role in the transplant system is occupied by organ procurement organizations (OPOs), which are federally designated non-profit organizations tasked with overseeing all aspects of organ donation within their specified geographic territory. Dedicated OPO professionals meet families in their darkest moments, and work to bring hope from tragedy. They are the bedrock upon which our system rests, and I offer them my sincerest thanks and gratitude.

The transplant system is built upon trust, and this trust has been broken through lack of oversight, backroom deals, retaliation against dissenting voices, misaligned metrics, and regulatory capture. Until recently, OPOs were allowed to self-determine which deaths within their territory represented potential donors (known as eligible deaths), leaving the door open for manipulation of the

performance metrics by which they were evaluated. Although CMS reformed this metric in 2022, the SRTR contractor refuses to recognize the reformed measure, and OPO lobbyists still oppose it. The OPTN contractor has similarly been allowed to control the collection and dissemination of data, essentially blinding HRSA to their true performance.

OPOs also lack sufficient oversight and accountability with regard to organ allocation, sometimes resulting in actions that are abusive and harmful to patients. I have had an OPO administrator recommend I proceed with organ procurement in the face of concerns a donor may still be alive. I have seen a 21-year old patient dying from liver failure have an ideal donor organ taken away from her by an OPO that was unwilling to provide one additional hour for a plane to be mobilized. Our complaint in this instance went unanswered. Unfortunately, stories such as these are not isolated instances. At present, approximately 20% of kidneys are allocated out of sequence, meaning patients with higher priority on the list were never given an opportunity to receive those organs. While this practice frequently reflects the best effort of a well-intentioned OPO to avoid organ wastage, the epidemic of out of sequence allocation represents a work around for failed policies that were pushed through a system rife with corruption.

I have read hundreds of pages of emails in which high ranking UNOS and OPTN officials, along with a small group of OPO and transplant physician leaders, scheme to undo years of evidence-based policy development in order to push through their own agenda instead. In the course of this process, individual OPTN executive committee members instructed their supposed regulators at HRSA on how to respond to threatened lawsuits in a manner that favored their agenda. Those who opposed this group were subject to retaliation and intimidation, people in large swaths of the country were derided with expletives by those in power in the OPTN/UNOS, and those patients suffering from organ failure who had not made it to the waiting list were dismissed as unimportant. Rather than being censured or removed

from office for this behavior, the CEO of UNOS was instead officially commended by the OPTN for his work.

The OPTN Modernization Act was intended to right the ship by separating the boards of the OPTN and its Contractor, and breaking up the OPTN contract. This process continues to be undermined, and the same actors remain in power. For example, the current president of the now "independent" OPTN board has a history of seeking to intimidate and retaliate against those who do not tow the OPTN party line, including those giving testimony to Congress such as I am today, and those who are unable to give testimony out of fear of further retaliation. HRSA officials who so willingly did the bidding of the OPTN remain in office, hindering effective change. With such resistance to reform, our transplant system can never reach its true potential, and patients suffering from organ failure are paying the price. The OPTN Modernization Act is a step in the right direction, but does not go far enough. Simply put, the OPTN has lost its way. In order to restore trust in the system, Congress must go further. Let me be clear that I am not requesting Congress to make medical policy. What I am asking is for a modernized NOTA which gives HRSA the tools to ensure that regulation and oversight are impartial, data based, and transparent. Only then will we be able to fully realize our mandate to serve *all* Americans suffering from organ failure.