Transforming Lives Through Organ, Tissue, and Eye Donation

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Before the U.S. House Committee on Energy and Commerce,
Subcommittee on Oversight and Investigations

"Ensuring Patient Safety: Oversight of the U.S. Organ Procurement and Transplant System"

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Chairman Joyce, Ranking Member Clarke, and Members of the Subcommittee, thank you for inviting Network for Hope, Inc. to testify at this hearing.

My name is Barry Massa, and I am the Chief Executive Officer of Network for Hope, the federally designated organ procurement organization (OPO) responsible for facilitating organ donation in Kentucky and parts of Ohio, West Virginia, and Indiana. Across 136 counties, Network for Hope serves nearly seven million people and partners with more than 185 hospitals (six of which are also transplant centers).

I have dedicated the majority of my professional life to honoring the selfless and courageous individuals and families who generously give the gift of life to one of the more than 100,000 individuals desperately waiting on the transplant waitlist. Last year, our team at Network for Hope made the gift of life possible recovering 1,035 organs, with 871 people receiving a life-saving transplant as a result.[1]

My career in this lifesaving mission began in 2004, when I joined LifeCenter Organ Donor Network (LifeCenter), the federally designated OPO that served the Greater Cincinnati area for more than 40 years, as its Chief Financial Officer. Four years later, I was named Executive Director, a role I proudly served in for 16 years. In October of 2024, I was honored to announce LifeCenter's merger with Kentucky Organ Donor Affiliates, Inc. (KODA), the federally designated OPO that served the State of Kentucky, and the formation of our combined entity, Network for Hope. Championed by the motto, "Better Together," LifeCenter and KODA's union leveraged collective strengths and longstanding legacies of excellence to expand a shared mission: to end the wait for those needing life-saving transplants. I consider it a true blessing and privilege to advance this mission every day.

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[1] Additional important statistics related to donation and transplantation are attached as <u>Exhibit 1</u>.

OPOs play a vital and unique role. By federal regulation, these community-based, not-for-profit organizations are exclusively designated to recover organs from deceased donors and facilitate transplantation to save as many lives as possible. The organ donation process in which OPOs operate is complex and multi-faceted. It begins when a hospital contacts its federally designated OPO with a potential donor (*i.e.*, a patient who has died or whose death is imminent). The OPO evaluates and determines donation eligibility, obtains authorization – either from the national donor registry (if the patient is a registered organ donor) or from the patient's legal next of kin – and conducts an evaluation of the potential donor to determine clinical suitability. If – and only if – the family of a potential donor has made the decision to withdraw life-sustaining treatment in consultation with the patient's independent health care provider, the OPO engages in a collaborative family discussion about donation. A potential recipient match is identified through the national transplant waiting list, overseen by the Organ Procurement and Transplantation Network (OPTN). Ultimately, an organ must be accepted by a transplant center; that decision belongs exclusively to the transplant center. If accepted, a recovery surgeon removes the organ, and the organ is transported to the transplant center by the OPO with care and respect. On receipt, the transplanting surgeon confirms suitability for the intended recipient and performs the lifesaving transplant. Thus, at their core, OPOs are the intermediaries in the donation and transplantation process. Thanks to their work, the United States has developed the most successful donation system in the world. Network for Hope does not take our role in this for granted; we are grateful to play a part.

At Network for Hope, we recognize that the organ donation system cannot succeed without public trust, and we appreciate the Subcommittee's continued bipartisan efforts to ensure that. We also are confident that continued improvement efforts are paramount in building public trust. That is why Network for Hope incorporated a number of improvements, enhancements, and best practices to maximize efficiencies and overall patient safety, as well as position leadership in certain areas to have fewer functions in order to maximize oversight. Moreover, Network for Hope has already incorporated some of the recent recommendations of the Heath Resources and Services Administration (HRSA) to the OPTN, such as a reassessment of the patient's neurological status every 12 hours.

Every business, every organization, and every team can and should always strive to be better. Network for Hope is no exception. We take our role and responsibilities extremely seriously, which is why we are constantly self-reviewing to identify if there are ways we can improve our processes, communicate more effectively with health care providers and families, and reduce waiting times for patients whose lives depend on receiving an organ donation. At the end of the day, the decisions that we as OPOs make can mean the difference in whether a family will be able to share another birthday with a loved one or have the opportunity to make more treasured memories with friends. None of this is lost on us – in fact, it is what drives our work *every single day*. The better we are, the more lives we save. And at Network for Hope, we not only welcome feedback, collaborative oversight, and stakeholder cooperation to continuously make our systems better, we insist on it.

We know that public trust must be earned, and that requires *all* stakeholders to be transparent, collaborative, and accountable to one another, the donors, the families, and the recipients that we collectively are privileged to honor and serve. It is critical that each of us does our part, and that we get it right, because while public trust is difficult to earn, it is easy to lose. That is why we must urge open and honest collaboration between stakeholders, promote accountability, and speak out against false statements and misinformation.

Unfortunately for the more than 100,000 individuals currently waiting to receive a lifesaving transplant, and the roughly 13 individuals who die each day without one,[2] these principles of public trust have been ignored by select stakeholders. As this Subcommittee is aware, during last September's hearing titled "A Year Removed: Oversight of Securing the U.S. Organ Procurement and Transplantation Network Act Implementation," certain individuals used this as a platform to promote serious, false, and never-before-reported allegations about KODA and a potential donation case in Kentucky from 2021. Specifically, it was alleged that in October 2021, KODA "pressured" staff to recover organs from a patient who had been declared brain dead but was still alive and moving around in the operating room as KODA staff were preparing for his organ recovery.

To be clear, prior to the hearing, to our knowledge, no one involved in the October 2021 case ever reported any such allegations to KODA or any other oversight authority. At KODA/Network for Hope, ensuring patient safety is the **top priority**, so these individuals' nearly three-year delay in disclosing any alleged patient safety concerns (regardless of their validity or invalidity) is alarming. We find it even more troubling that the allegations were first shared with the media, which then amplified and inflamed the *false* allegations, greatly diminishing and damaging public trust. As a result of this misinformation campaign in the media, more than 1,000 donors removed their names from the Kentucky Donor Registry in October alone.

Removals from Kentucky Donor Registry:

2024	
September	305
October	1,076
November	467
December 2024	330
TOTAL	**2,178**

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[2] The U.S. Organ Donation & Transplantation System | UNOS.

KODA and Network for Hope vehemently deny these accusations and want to make a few things abundantly clear:

- OPOs *do not* recover organs from living patients.
- OPOs *are not* involved nor have any say in the declaration of a patient's death.
- OPOs only facilitate the recovery process from *deceased* patients.
- OPOs *do not* recover organs from a patient *unless and until* the patient's health care provider has declared death.
- OPOs *do not* provide health care.
- OPOs *do not* participate in the decision to withdraw life-sustaining care.
- OPOs *do not* order or administer pain medication or sedatives to patients.
- OPOs *do not* pressure health care providers to make health care decisions.

Throughout the months that followed the September hearing, KODA (and, after October 1, Network for Hope) fully and timely cooperated with every request it received from oversight and enforcement agencies for documents and information related to the October 2021 patient.[3] In late September, the OPTN's Membership and Professional Standards Committee (MPSC) closed its investigation into the October 2021 case without action. Then, a specially selected ad hoc review committee of the OPTN concluded, after its review of the October 2021 case and dozens of other KODA cases, that there were "*no major concerns or patterns*." To the contrary, the ad hoc review committee reported as follows:

> "The reviewers would like to ***commend*** *[KODA]* on their *support for patient families, particularly through complex DCD cases that may not result in donation*. Cases and processes were *well documented*, including conversations with families, case touchpoints, staff time, and rationale for decisions. Additionally, [KODA's] structured

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[3] CMS conducted an onsite complaint survey at Network for Hope in October 2024. As a result, and in addition to enhancements already made, Network for Hope revised its donation after circulatory death (DCD) policies and practices, primarily related to improving documentation, monthly auditing, internal communication, and hospital education. CMS revisited Network for Hope in May 2025 and found it to be in compliance.

> approach to involving medical directors and administrators when issues arose was *commended*."

On June 4, 2025, Network for Hope was made aware of a letter that HRSA had sent to the OPTN on May 28, 2025 (HRSA Letter), claiming that "concerning features" in a subset of DCD[4] cases created "the potential for ongoing risk of harm to patients in K[O]DA's DSA." HRSA's Letter and its underlying report to the Associate Administrator (HRSA Report) (which was dated months earlier but was not shared with Network for Hope until this hearing was scheduled) did not cite any OPTN policy, regulation, statute, or rule that it claims Network for Hope violated – nor could it, because one does not exist. Moreover, HRSA did not allege any specific *wrongdoing* by KODA/Network for Hope; it vaguely stated that it found "concerning features" (which are not described) in some DCD cases (which are not identified). Despite requests, HRSA has declined to provide this information to Network for Hope.

If HRSA has believed – *for months* – that there is an "ongoing risk of harm to patients in [KODA's] [Donation Service Area]," as it baldly contends in its correspondence to the OPTN, it was incumbent upon it, as the health oversight agency, to immediately notify Network for Hope, identify the specific "concerns," and require prompt correction/remediation. Instead, HRSA sat on its report and purported patient safety concerns for months, and then shared them not with Network for Hope, but with *The New York Times* (only).[5]

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[4] *See* "The Two Pathways to Deceased Organ Donation," Association of Organ Procurement Organizations, attached as Exhibit 2.

[5] "*Doctors Were Preparing to Remove Their Organs. Then They Woke Up.*" N.Y. Times, June 6, 2025 (reporting that HRSA had shared its findings and report with *The New York Times*). Of note, Network for Hope was denied access to the HRSA Report for months – until July 9, 2025 – and only then obtained a copy of it after asking this Subcommittee's staff for assistance.

This hearing and oversight effort shows a clear breakdown in the existing regulatory framework. It should not take months or the explicit direction of this Subcommittee to get a report that contains concerning allegations , including ones that suggest potential “ongoing” risks to patient safety, to an OPO. The lack of communication, collaboration, and transparency hurts the governmental oversight process and the organ donation and transplantation system as a whole.

I readily admit that Network for Hope takes just as much ownership as HRSA and other stakeholders in acknowledging areas that require improvements within the system. The HRSA Report provides an opportunity for all parties to improve and implement best practices for the betterment of patients, donors, families, partners, oversight bodies, and the donation system as a whole.

Patient safety is at the forefront of everything OPOs do. But OPOs cannot meaningfully or appropriately address alleged patient safety concerns if they do not receive timely and comprehensive feedback from oversight agencies. Network for Hope remains committed to implementing any and all improvements or enhancements deemed necessary so that it can continue to advance and fulfill its mission to save lives – but it needs collaboration, transparency, and accountability from the appropriate oversight agencies to do that. Likewise, Network for Hope is fully committed to working with all stakeholders, especially families, hospitals, and oversight agencies, to improve the national system so that we can collectively serve those in need. **We are Better Together**.

So why does all of this matter, and why am I here today?

I had a friend whose children went to the same grade school as me, and we belonged to the same church. They had a daughter, Audrey, who had several major health issues at birth, which eventually required her to get a double lung and heart transplant. At 18 months old, Audrey was life-flighted from Cincinnati to the Children’s Hospital of Philadelphia. She received her double-lung and heart transplant, and the family lived in a Ronald McDonald house in Philadelphia for several months. Audrey lived for another 18 months before unexpectedly passing away from lung rejection. Upon her passing, Audrey became a cornea donor.

Years later, I saw an advertisement for a Chief Financial Officer position at LifeCenter and its affiliated tissue bank, U.S. Tissue and Cell. I called my friend who tragically lost their daughter, because I had no idea that OPOs existed; I assumed this all happened at the hospital. My friend told me, “Barry, you are what they need,” and so I applied.

Sitting before you today, I have humbly been working for the last two decades to honor Audrey’s memory, advocating for all who are on the transplant waitlist. I am proud of this work and the many individuals I work alongside at Network for Hope and across the country at other OPOs who truly help make the gift of life possible. This is an important mission and one I feel called and compelled to do each day.

We respectfully urge the Subcommittee to encourage ***all*** policymakers and stakeholders to honor the tenets of the OPTN Modernization Act and work together positively and with transparency and accountability to restore, and ensure, public trust in the system and process that literally mean the difference between life and death.