"A Year Removed: Oversight of Securing the U.S. Organ Procurement and Transplantation Network Act Implementation" Major Points of Prepared Testimony to the House Energy and Commerce Oversight and Investigations Subcommittee September 11, 2024 Seth J. Karp, MD

Thousands of patients continue to die in the U.S. waiting for an organ due to the self-interest, incompetence, corruption, and mismanagement at OPTN. If we get the policy right, there are enough organs in the U.S. for everyone who needs a liver, heart, or lung, and enough kidneys to dramatically decrease the waiting times for those who need one.

Research shows the number of organs available could be increased so that few if any patients would die waiting for an organ.

The OPTN, which manages transplantation in the United States, has been captured by the industry it is supposed to oversee. The Boards of the oversight body (OPTN) and the contractor (UNOS) have been the same. This egregious conflict of interest allowed industry insiders to fill positions of power, prevent enforcement of the statutes, and permit special interests to control the system.

The OPTN Board has acted in bad faith. In broad daylight they ignore research showing donation could be dramatically improved, claim they cannot oversee OPO performance, lobby against bipartisan, data-driven measures, suppress data, and continue to ignore the harm to the system caused by their policies, especially disadvantaged and rural patients. In back rooms, OPTN assures no OPO will be held accountable for performance, prevents competition, threatens to sabotage any new contractor, manipulates board members, intimidates community members, minimizes data breaches and errors, denigrates suffering patients in rural and poorer areas of the U.S., and does not sufficiently prioritize the needs of children.

I recommend this body ensure:

- HRSA instructs OPTN to renew its focus on donation
- HRSA appoints a new OPTN Board
- The OPO Final Rule is enforced
- The OPTN contracting process occurs with full accountability and open data access
- HHS ensures that the OPTN is held accountable for its performance