

# ***"A Year Removed: Oversight of Securing the U.S. Organ Procurement and Transplantation Network Act Implementation"***

## **Prepared Testimony to the House Energy and Commerce Oversight and Investigations Subcommittee**

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Chairman Griffith, Ranking Member Castor, and Members of the Committee, thank you for your oversight on this life-and-death issue.

Organ donation is deeply personal for me. My father waited five years for a heart transplant, needing three open-heart surgeries just to survive – he was literally in the car to see an end-of-life counselor when a heart finally became available for him.

Nine months later my aunt received a heart transplant as well, which is when we learned that we have a very rare genetic condition in our family that causes heart failure. A few years later, another of my aunts died in need of a heart, and I now have two siblings and three cousins who will very likely need heart transplants as well.

To help families like mine, I founded Organize, a patient advocacy non-profit, which advocates for reforms to increase accountability in the organ donation system, and from 2015-2016, we served in a policy development role in the Department of Health and Human Services (HHS).

It was during our time at HHS that I became overwhelmed with whistleblower allegations of widespread abuse within the Organ Procurement and Transplantation Network (OPTN), including credible allegations of:

- Rampant Medicare Fraud, including organ procurement organization (OPO) executives joyriding on taxpayer-funded private jets intended for the transportation of organs, and the ordering of unnecessary lab testing in order to overbill Medicare;
- Unsafe patient care, including the hastening of death with fentanyl and the falsification of medical records, as well as lying to donor families;
- The harvesting of organs from patients who whistleblowers believe would otherwise have survived;
- The fraudulent harvesting of pancreases for research in order to subvert CMS regulations, and of kidneys to facilitate the excess billing of Medicare;

- Preferencing white, wealthy, and famous people on the organ transplant waiting list by skipping over other patients higher up on the waiting list;
- Kickback schemes between OPO executives and tissue processors, aviation companies, and medical device companies;
- Systemic OPO practices of burying damning information via taxpayer funded NDAs or out of court settlements;
- OPO executives directing staff to deprioritize care for Black patients, often using derogatory language I will not repeat here or elsewhere; and
- OPTN leaders attempting to solicit bribes from other OPTN members in exchange for inappropriately clearing them of any wrongdoing in investigations pertaining to patient safety lapses.

To be clear, while I have found these allegations credible, and in some cases have received extensive supporting documentation, I am not an oversight body, and do not have the capacity to investigate these claims myself – though I would greatly appreciate the opportunity to work with this Committee to pursue additional oversight into some of these egregious abuses.

And while the individual whistleblower allegations differed, I was struck most that all of these whistleblowers all still told me the same thing: that they were reaching out to me, rather than to the OPTN, because they had absolutely no faith in the OPTN process; that their complaints would just get buried; and that they would suffer career-ending retaliation simply for raising these issues in the first place.

So I instead began referring whistleblowers to Congressional oversight bodies, and, as appropriate, to law enforcement. That’s when industry interests came after me, too.

A lobbyist for the New Jersey OPO launched an offensive and antisemitic astroturf campaign falsely implying that I am lying that my aunt died in need of a heart transplant, and that I harbor undisclosed financial motivations, including that I am planning to sell human organs for profit.

As this Committee well knows, these allegations are categorically false, and I have absolutely no financial interest in any organ donation reforms.

But that did not stop Dr. Rich Formica, now OPTN president, from sharing this astroturf campaign in a national op-ed, which is when things became even worse.

Friends at OPOs told me that their colleagues would brag about their intentions to purposefully mismanage my care, to “dismember me”, and to “make me unrecognizable to my own mother.”

I’ve been told that if I don’t stop my advocacy, that my brother and sister will never get transplants.

This has been the personal cost of advocating for higher standards of patient care; the cost of being an older brother who is just trying to save his little brother and sister.

OPOs are a multi-billion dollar taxpayer-funded industry of unaccountable body brokers, and the whistleblower retaliation is a feature, not a bug. The current OPTN structure not only protects industry interests, but actively incentivizes and even rewards these abhorrent behaviors.

The question is far beyond whether the OPTN has failed patients, but whether such failures rise to the level of gross or even criminal negligence.

The solutions are clear: holding HRSA accountable by ensuring the intent of H.R. 2544, the law this committee worked tirelessly to pass in a unanimous, bipartisan effort, is realized by:

- Breaking up monopoly control through competitive, accountable contracts;
- Appointing an OPTN board that is truly independent of industry control and financial conflicts; and
- Seeing through oversight of every credible allegation of fraud and patient abuse so that perpetrators are brought to justice, and patients have the safe, effective organ donation system they deserve.

I would like to close by thanking the Committee for its oversight, and all it can do to see these reforms through.