## After explosive federal report, Congress fears plummeting trust in organ donation

A House oversight panel criticized major players in the organ transplant network



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WASHINGTON — Members of a congressional oversight committee said Tuesday that they fear public trust in organ donation has been fractured after a federal report found that an organ procurement organization ignored signs of life in patients when authorizing attempted organ removals.

The hearing followed a <u>federal investigation by the Health Resources and Services Administration</u> that found that a group responsible for overseeing the removal of organs from deceased patients and getting them to patients in need exhibited "concerning patterns of risk to neurologically injured patients."

"For every doctor, the most important tenet in the patient-physician relationship is above all, do no harm, but what happened in these cases fractured the physician-patient relationship and saw patients subjected to pain and suffering that never should have occurred," House Energy and Commerce Oversight and Investigations subcommittee Chair Rep. John Joyce (R-Pa.) said in his opening statement.

HRSA investigated more than 350 attempted organ removals authorized by Kentucky Organ Donor Affiliates, now known as Network for Hope, and found "concerning features" in nearly 30% of cases in which organ procurement was attempted but not completed.

HRSA threatened to de-certify the group if corrective actions aren't taken.

The federal investigation was spurred by a hearing held by the same committee last fall where patient advocates and transplant surgeons alleged that the organizations responsible for acquiring and transplanting organs were negligent and corrupt. Greg Segal, founder of the patient-advocacy nonprofit Organize, detailed the case of a patient in Kentucky who woke up while having his organs recovered after signoff by the group now known as Network for Hope.

On Sunday, the New York Times <u>published an article detailing other</u> <u>similarly chilling cases</u> of patients who woke up during organ recovery attempts, based on interviews with patients and medical staff.

In response to the federal report, Health and Human Services Secretary Robert F. Kennedy Jr. has promised a "major initiative" to reform the organ transplant system and improve safety monitoring by the Organ Procurement and Transplantation Network, or OPTN.

The 40-year-old transplant system is already in the midst of a major overhaul started by the Biden administration. <u>Under a 2023 law</u>, management of the OPTN was taken out of the hands of its longtime sole vendor, the private nonprofit United Network for Organ Sharing. Instead HRSA began soliciting contractors to run parts of the massive system that oversees tens of thousands of transplants per year.

HRSA also ordered that the system's board of directors — once the same as UNOS' own — be made into a separate, independent entity.

During Tuesday's hearing, lawmakers sharply questioned and criticized the practices of Network for Hope, the OPTN, and UNOS in conducting oversight of patient safety. The OPTN had launched a separate investigation into Network for Hope that was closed without further action.

Lawmakers fretted that the HRSA and New York Times reports would discourage people from becoming organ donors.

"I'm very concerned about ... how this is going to impact the general public's decision to donate their organs," Rep. Gary Palmer (R-Ala.) told UNOS CEO Maureen McBride.

When asked by Rep. Diana DeGette (D-Colo.) whether the OPTN stood by that original report, former president Richard Formica said the group's inquiry shouldn't have been closed so quickly, but added that OPTN policies limited the investigation.

"We need a more robust process," current OPTN President John Magee later said. He called OPTN just a "sliver" of the overall network.

McBride has <u>said in response to the New York Times report</u> that oversight of the organ network is "fragmented" between HRSA and the Centers for Medicare and Medicaid Services, which certifies organ procurement organizations.

Segal wants Congress and HHS to remove bad actors from the system more quickly.

"HRSA's patient safety team did excellent work on the Kentucky case, but, as the New York Times showed, this is happening all over the country. HHS needs to give them resources to investigate across the country, and then CMS has to be prepared to take immediate action to replace dangerous [organ procurement organizations]," he told STAT.

Jennifer Erickson, senior fellow with the Federation for American Scientists and an Obama administration alum, echoed Segal's point.

"I'm grateful that Secretary Kennedy acknowledged that organ contractors are failing our most vulnerable Americans in the most horrific of ways. The only way to keep Americans safe is to immediately replace corrupt and negligent organ contractors," she told STAT