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Brian M. Shepard Executive Director & CEO

April 28, 2022

The Honorable Raja Krishnamoorthi, Chairman Subcommittee on Economic and Consumer Policy Committee on Oversight and Reform U.S. House of Representatives Washington, DC 20515

## VIA ELECTRONIC MAIL

Dear Chairman Krishnamoorthi:

We are writing to inform you that United Network for Organ Sharing (UNOS) was contacted by two prominent national media organizations about an "embargoed government report" regarding the U.S. organ donation and transplantation system prepared by your subcommittee. We have not seen the report. In the interest of the entire donation and transplant community and our patients, we urge you to gain a comprehensive fact-based understanding of this community's lifesaving work. As a transplant surgeon at Medstar Georgetown and President of UNOS, and a transplant nephrologist at Jefferson Health and Vice President of UNOS, we are writing to offer our assistance and to provide some additional information for your consideration.

The questions posed by the outlets included excerpts of data from the unreleased report that drew a false conclusion from a misunderstanding of how the organ donation and transplant system functions. We are concerned that an embargoed copy of such a factually flawed report was released to prominent reporters and could still be released to the general public.

It is our understanding that the report concludes that some of the nonprofits responsible for facilitating organ donations, organ procurement organizations (OPOs), are missing the "vast majority" of opportunities for donation. Based on the statistics shared with us by the press, it appears as though the report assumes that every person who has died in a hospital is a "potential donor," even if they were not medically cleared to be an organ donor. In fact, less than 1% of all deaths in the U.S. occur in ways clinically compatible with organ donation; people who die of cancer, sepsis, certain infectious diseases, or organ failure are ruled out for donation by the OPO using medical criteria established by transplant physicians for the safety of the potential recipient.

The effect of suggesting that OPOs should seek donation authorization for every in-hospital death would have them approaching grieving families about organ donation – even when the OPO had already determined that that donation was not a clinical possibility. Giving false hope to families at such a difficult time would not just be inefficient, it would be cruel.

This is not the first time that the organ donation and transplant system has been the subject of criticisms based on inaccurate data. A small group of critics has been circulating a series of opeds, self-funded research, and out-of-context references to paint the world's highest-performing organ donation and transplant system as ineffective. When they do quote legitimate peer-

reviewed research, it is often twenty years old or older, describing a system that only exists in the distant past.

Here are the real facts about organ donation and transplant in the United States:

- The number of deceased-donor transplants has increased every year for the last nine consecutive years even during the pandemic to a record high of 41,356 transplants in 2021.<sup>1</sup>
- We have the highest performance of any organ donation and transplant system in the world, in total donations and transplants, and adjusted for population.<sup>2</sup>
- The U.S. transplant waitlist has fewer people on it today than at any point in the last 15 years.<sup>3</sup>
- The policies that determine a person's priority on the waiting list are written by a unique consensus-based system of doctors, patients, and other professionals working together.<sup>4</sup>
- Those allocation policies are constantly measured for equity, with results publicly reported.<sup>5, 6, 7, 8</sup>
- The OPTN's publicly available Equity in Access Dashboard shows that differences in patient gender, ethnicity, education, income, or rural/urban residency each account for less than 5% of the variation in likelihood of getting a transplant among waitlisted kidney candidates.<sup>9</sup>
- Current U.S. organ donation family/donor authorization rates average 70%.<sup>10</sup>

<sup>&</sup>lt;sup>1</sup> "All-time records again set in 2021 for organ transplants, organ donation from deceased donors." 11 January 2022. Organ Procurement and Transplantation Network. <u>https://optn.transplant.hrsa.gov/news/all-time-records-again-set-</u> in-2021-for-organ-transplants-organ-donation-from-deceased-donors/.

<sup>&</sup>lt;sup>2</sup> "International Registry of Organ Donation and Transplant." February 2021.

https://www.irodat.org/img/database/pdf/Irodat%20December\_final%202020.pdf

<sup>&</sup>lt;sup>3</sup> "OPTN Data: Waiting List." Organ Procurement and Transplantation Network. https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/

<sup>&</sup>lt;sup>4</sup> "OPTN Policy Development Process." Organ Procurement and Transplantation Network. https://optn.transplant.hrsa.gov/policies-bylaws/policy-development/#policyProcess.

<sup>&</sup>lt;sup>5</sup> Eliminate Use of DSA and Region from Kidney Allocation: 6 Month Post-Implementation Report." 8 Oct. 2021. Organ Procurement and Transplantation Network. <u>https://optn.transplant.hrsa.gov/news/updated-monitoring-report-</u>available-for-kidney-allocation-policies/.

<sup>&</sup>lt;sup>6</sup> "Eliminate Use of DSA and Region from Liver and Intestine Allocation: 18 Month Post-Implementation Report." 14 Dec. 2021. <u>https://optn.transplant.hrsa.gov/news/updated-monitoring-report-now-available-for-liver-intestine-policy/</u>.

<sup>&</sup>lt;sup>7</sup> "One Year Monitoring of Heart Allocation Proposal." 20 Feb. 2020.

https://optn.transplant.hrsa.gov/media/3701/data\_report\_thoracic\_committee\_heart\_subcommittee\_20200227\_rpt 1\_revised\_508\_compliant.pdf.

<sup>&</sup>lt;sup>8</sup> "Monitoring of the Lung Allocation Change, 2 Year Report Removal of DSA as Unit of Allocation." 12 Feb. 2020. <u>https://optn.transplant.hrsa.gov/media/3661/item\_25\_thoracic\_committee\_20200212.pdf</u>.

<sup>&</sup>lt;sup>9</sup> "OPTN Equity in Access Dashboard." Organ Procurement and Transplantation Network. https://optn.transplant.hrsa.gov/data/visual-dashboards/equity-in-access/.

<sup>&</sup>lt;sup>10</sup> "U.S. Organ Procurement Organization Donation Principles, Laws and Practices." 25 Sept. 2020. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7516933/.

- UNOS, the nonprofit that serves as the national allocation system, uses cutting edge technology, machine learning, and behavioral science analysis to get the right organ to the right patient at the right time.<sup>11</sup>
- The secure patient data system UNOS operates protects sensitive information from over 3 million hacker attempts every day.

The U.S. organ donation and transplant system is a model for the rest of the world. However, despite our successes, there are still more patients waiting for transplants than there are available organs. The system needs to continue to improve. Lives literally depend on it.

At the request of Congress, a National Academies of Science, Engineering, and Medicine (NASEM) committee comprised of a broad cross-section of donation and transplant professionals studied the U.S. transplant system and recognized recent innovations in transplant policymaking and produced thoughtful recommendations, many of which we view as a blueprint forward.

The way we will improve is by working together, with good facts and in good faith, to build on the strong system already in place. Baseless attacks that mislead decision-makers, weaken public trust, and divert time and resources from the real challenges of increasing organ donation do not move us any closer to our goal of eliminating the transplant waiting list. Only fact-based analysis, collaboration and a shared commitment to the patients who are waiting will improve the system.

Sincerely,

Matthew Cooper, MD President, UNOS Board of Directors

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Jerry McCauley, MD, MPH Vice President, UNOS Board of Directors

CC: The Honorable Carolyn Maloney, Chairman, House Committee on Oversight and Reform

The Honorable James Comer, Ranking Member, House Committee on Oversight and Reform

The Honorable Michael Cloud, Ranking Member, Subcommittee on Economic and Consumer Policy, House Committee on Oversight and Reform

<sup>&</sup>lt;sup>11</sup> How Technology is Transforming Organ Procurement. 22 Sept. 2021. <u>https://techcrunch.com/2021/09/22/how-technology-is-transforming-organ-procurement/</u>.