

# Congress of the United States

## House of Representatives

COMMITTEE ON OVERSIGHT AND REFORM

2157 RAYBURN HOUSE OFFICE BUILDING

WASHINGTON, DC 20515-6143

MAJORITY (202) 225-5051

MINORITY (202) 225-5074

<http://oversight.house.gov>

December 23, 2020

Mr. Steve Miller  
Chief Executive Officer  
Association of Organ Procurement Organizations  
8300 Greensboro Drive, #L1-620  
McLean, VA 22102

Dear Mr. Miller:

The Subcommittee on Economic and Consumer Policy seeks documents and information about the activities of the Association of Organ Procurement Organizations (AOPO) with respect to certain recent proposed regulations from the Department of Health and Human Services (HHS). It has been reported that the Association and its members are lobbying against reforms that would bring much-needed improvement and accountability to the organ-transplantation industry, which has distressing reports of mismanagement, waste, and abuse.

### **Shocking Mismanagement Reported in Organ Procurement**

Nationally, there are 58 Organ Procurement Organizations (OPOs). According to one white paper, each of these OPOs “operates as an unchecked regional monopoly,” and performance levels across OPOs are highly variable.<sup>1</sup> There is an “astounding lack of accountability and oversight in the nation’s creaking, monopolistic organ transplant system,” which is “allowing hundreds of thousands of potential organ donations to fall through the cracks.”<sup>2</sup> One research analysis estimated there may be up to 28,000 available organs from deceased donors annually that are not ultimately transplanted into patients who need them, which equates to around 25,000 lives that are not saved even when organ donors are located.<sup>3</sup> The

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<sup>1</sup> The Bridgespan Group, *Reforming Organ Donation in America: Saving 25,000 Lives Per Year and \$13 Billion in Taxpayer Funds over Five Years* (updated Jan. 2019) (online at [www.bridgespan.org/bridgespan/Images/articles/reforming-organ-donation-in-america/reforming-organ-donation-in-america-12-2018.pdf](http://www.bridgespan.org/bridgespan/Images/articles/reforming-organ-donation-in-america/reforming-organ-donation-in-america-12-2018.pdf)).

<sup>2</sup> Editorial Board, *She Beat Cancer. Now, She’s in Another Fight for Her Life.*, New York Times (Aug. 20, 2019) (online at [www.nytimes.com/2019/08/20/opinion/erika-zak-organ-donor.html](http://www.nytimes.com/2019/08/20/opinion/erika-zak-organ-donor.html)).

<sup>3</sup> The Bridgespan Group, *Reforming Organ Donation in America: Saving 25,000 Lives Per Year and \$13 Billion in Taxpayer Funds over Five Years* (updated Jan. 2019) (online at [www.bridgespan.org/bridgespan/Images/articles/reforming-organ-donation-in-america/reforming-organ-donation-in-america-12-2018.pdf](http://www.bridgespan.org/bridgespan/Images/articles/reforming-organ-donation-in-america/reforming-organ-donation-in-america-12-2018.pdf)).

burden of OPO failures is disproportionately borne by patients of color, making OPO reform an urgent health care equity issue.<sup>4</sup>

This waste results from various problems afflicting OPOs and the United Network for Organ Sharing (UNOS), which operates as the national Organ Procurement Transplantation Network (OPTN). There are reports of gross mismanagement, such as the failure to hire enough staff to respond to all donation cases.<sup>5</sup> UNOS is plagued by reports of serious lapses in quality control, such as allowing a “startling number” of transplantable organs to be lost, damaged, or delayed in transit—including mistakenly being left on airplanes—to the extent that they become degraded and must be discarded or otherwise result in worse outcomes for patients.<sup>6</sup> There are also reports of financial impropriety.<sup>7</sup>

Meanwhile, OPOs have reportedly misrepresented their efficiency at finding and collecting potential transplantable organs.<sup>8</sup> OPOs have self-reported their performance measures, and expert analysis has shown that the vast majority of OPOs significantly exaggerate their organ procurement rates, and their recovery rates are significantly lower than reported.<sup>9</sup> This has led prominent healthcare analysts and scientists, such as Dr. DJ Patil, the former Chief Data Scientist of the United States, to refer to current data from OPOs as “functionally useless.”<sup>10</sup> APOPO has even claimed that “self-reported” data could not be used to decertify an OPO because “accuracy and consistency of data cannot be assured.”<sup>11</sup>

This litany of reports is an indictment against the industry and demonstrates the need for reform.

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<sup>4</sup> Bloom Works, *The Costly Effects of an Outdated Organ Donation System: Inequity in Organ Donation* (online at <https://bloomworks.digital/organdonationreform/Inequity>).

<sup>5</sup> *Underperforming in New York: Nonprofit Struggles to Recover Transplantable Organs*, Washington Post (Dec. 20, 2018) (online at [www.washingtonpost.com/national/underperforming-in-new-york-nonprofit-struggles-to-recover-transplantable-organs/2018/12/20/55475aea-fa5c-11e8-863c-9e2f864d47e7\\_story.html](http://www.washingtonpost.com/national/underperforming-in-new-york-nonprofit-struggles-to-recover-transplantable-organs/2018/12/20/55475aea-fa5c-11e8-863c-9e2f864d47e7_story.html)).

<sup>6</sup> *How Lifesaving Organs for Transplant Go Missing in Transit*, Kaiser Health News (Feb. 10, 2020) (online at <https://khn.org/news/how-lifesaving-organs-for-transplant-go-missing-in-transit/>).

<sup>7</sup> *Taxpayers Help Pay for Organ Donor Groups’ Parties, Rose Parade Expenses*, Trib Live (Oct. 19, 2013) (online at <https://archive.triblive.com/local/pittsburgh-alleggheny/taxpayers-help-pay-for-organ-donor-groups-parties-rose-parade-expenses/>).

<sup>8</sup> *Video Op-Ed: 11,000 American Patients Will Die This Year Waiting for Transplants*, New York Times (June 11, 2019) (online at [www.nytimes.com/2019/06/11/opinion/organ-transplant-deaths.html](http://www.nytimes.com/2019/06/11/opinion/organ-transplant-deaths.html)).

<sup>9</sup> The Bridgespan Group, *Reforming Organ Donation in America: Saving 25,000 Lives Per Year and \$13 Billion in Taxpayer Funds over Five Years* (updated Jan. 2019) (online at [www.bridgespan.org/bridgespan/Images/articles/reforming-organ-donation-in-america/reforming-organ-donation-in-america-12-2018.pdf](http://www.bridgespan.org/bridgespan/Images/articles/reforming-organ-donation-in-america/reforming-organ-donation-in-america-12-2018.pdf)).

<sup>10</sup> Laura and John Arnold, *A Simple Bureaucratic Organ Donation Fix Will Save Thousands of Lives*, STAT, (July 23, 2019) (online at [www.statnews.com/2019/07/24/a-simple-bureaucratic-organ-donation-fix-will-save-thousands-of-lives/](http://www.statnews.com/2019/07/24/a-simple-bureaucratic-organ-donation-fix-will-save-thousands-of-lives/)).

<sup>11</sup> *Despite Low Performance, Organ Collection Group Gets New Federal Contract*, Washington Post (Feb. 10, 2019) (online at [www.washingtonpost.com/national/despite-low-performance-organ-collection-group-gets-new-federal-contract/2019/02/04/9b9ba2aa-2895-11e9-b2fc-721718903bfc\\_story.html](http://www.washingtonpost.com/national/despite-low-performance-organ-collection-group-gets-new-federal-contract/2019/02/04/9b9ba2aa-2895-11e9-b2fc-721718903bfc_story.html)).

## **Health Authorities Attempt to Reform the Organ Procurement System**

On July 10, 2019, President Trump signed an executive order titled “Advancing American Kidney Health,” to “establish more transparent, reliable, and enforceable objective metrics for evaluating an OPO’s performance.”<sup>12</sup> On December 17, 2019, HHS announced a proposed rule from the Centers for Medicare and Medicaid Services (CMS) to improve OPO performance metrics and accountability.<sup>13</sup> On November 20, 2020, CMS finalized a rule to enforce new objective measures for donation and transplantation, update those benchmarks based on national OPO performance, allow for some competition for OPOs with middling performance, and require more frequent recertification reviews.<sup>14</sup>

In explaining the need for its rule, HHS found that OPOs may be choosing not to pursue procurement of organs from single-organ donors because the OPOs want an increased organs-per-donor metric. This means that life-saving organs are not collected. As HHS itself projected, compliance with the new OPO performance measures would lead to 5,600 to 7,300 additional organ transplants per year.<sup>15</sup>

Tens of thousands of patients are currently being underserved by poor-performing OPOs, and 33 Americans die every day for lack of an organ transplant. For these reasons, we look forward to working with you and the incoming Administration to accelerate enforcement of the final rule and begin decertifying failing OPOs as soon as possible.<sup>16</sup>

## **AOPO and OPOs Lobbied Against Proposed Reforms**

In response to this rule, AOPO has seemingly “ratcheted up dramatically” its lobbying expenditures to oppose the Executive Order and HHS’s proposed rule. One OPO executive stated at an official UNOS meeting that it was “fortunate” that federal agencies were dealing with the coronavirus, because that would allow OPOs to mount a “real congressional action campaign” to oppose new reforms. While AOPO, its members, and affiliated organizations spent a total of only about \$160,000 per year on lobbying in 2017 and 2018 combined, their spending nearly tripled in 2019 to \$452,000. In the first half of 2020, lobbying expenditures had already reached \$450,000. AOPO reportedly told its members that it would change its nonprofit

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<sup>12</sup> Exec. Order No. 13879 (July 10, 2019) (online at [www.whitehouse.gov/presidential-actions/executive-order-advancing-american-kidney-health/](http://www.whitehouse.gov/presidential-actions/executive-order-advancing-american-kidney-health/)).

<sup>13</sup> Department of Health and Human Services, *Press Release: Trump Administration Proposes New Rules to Increase Accountability and Availability of the Organ Supply* (online at [www.hhs.gov/about/news/2019/12/17/trump-administration-proposes-new-rules-increase-accountability-availability-organ-supply.html](http://www.hhs.gov/about/news/2019/12/17/trump-administration-proposes-new-rules-increase-accountability-availability-organ-supply.html)).

<sup>14</sup> Centers for Medicare and Medicaid Services, *Organ Procurement Organization (OPO) Conditions for Coverage Final Rule: Revisions to Outcome Measures for OPOs CMS-3380-F* (Nov. 20, 2020) (online at [www.cms.gov/newsroom/fact-sheets/organ-procurement-organization-opo-conditions-coverage-final-rule-revisions-outcome-measures-opos](http://www.cms.gov/newsroom/fact-sheets/organ-procurement-organization-opo-conditions-coverage-final-rule-revisions-outcome-measures-opos)).

<sup>15</sup> *Id.*

<sup>16</sup> Editorial Board, *Many Die Waiting for Organs*. (Aug. 1, 2020) (online at [www.washingtonpost.com/opinions/many-die-waiting-for-organs-the-trump-administration-could-help/2020/07/31/77e3a102-dfd6-11e9-b199-f638bf2c340f\\_story.html](http://www.washingtonpost.com/opinions/many-die-waiting-for-organs-the-trump-administration-could-help/2020/07/31/77e3a102-dfd6-11e9-b199-f638bf2c340f_story.html)).

status from 501(c)(3) to (c)(6) to allow for freer spending on lobbying.<sup>17</sup> OPOs in Los Angeles, Chicago, New England, Philadelphia, Houston, Seattle, Minnesota, and Nashville began lobbying last year under a new coalition, the Organ Donation Advocacy Group.<sup>18</sup>

While AOPO and the OPO industry have been lobbying against life-saving reforms, they have also engaged in lobbying efforts to receive federal funding intended to support frontline healthcare workers and struggling small businesses during the coronavirus pandemic. Under the Coronavirus Aid, Relief, and Economic Security (CARES) Act, Congress established the \$175 billion Provider Relief Fund to support frontline health care providers.<sup>19</sup> AOPO requested from HHS that OPOs be given some of these discretionary funds, contending that “the Congressional intent of the Act is to provide an influx of funds to the healthcare industry, which the federally regulated OPOs service.”<sup>20</sup> An investigative report found that while AOPO and OPOs “battle Trump’s plan, some in the industry have been approved for what may total more than \$100 million” in Paycheck Protection Program (PPP) loans intended for struggling small businesses, “even though, in some cases, organ procurement industry borrowers involved in the lobbying are sitting on large financial assets, expensive real estate, or other reserves, in one case valued at more than \$112 million.”<sup>21</sup>

To assist the Subcommittee in its review of this matter, please provide the following information by January 13, 2021:

1. All documents related to meetings of the AOPO board of directors, including agendas, meeting minutes, and presentation slide decks, since January 1, 2018;
2. All documents related to CMS’s 2019 proposed OPO rule, including emails and other documents created by or for AOPO’s Executive Committee or Legislative and Regulatory Affairs Committee, emails and other communications with UNOS, and emails and other communications with the federal government;
3. All documents related to AOPO’s decision to change its legal incorporation status from 501(c)(3) to 501(c)(6); and
4. All documents related to AOPO and its members’ application for and acceptance of funds under the CARES Act and other legislation passed by Congress for

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<sup>17</sup> *Heartless: Organ Donation Contractors Lobby Against a Popular Health Care Initiative*, Project on Government Oversight (Oct. 5, 2020) (online at [www.pogo.org/investigation/2020/10/heartless-organ-donation-contractors-lobby-against-a-popular-health-care-initiative-while-pocketing-pandemic-relief-loans/](http://www.pogo.org/investigation/2020/10/heartless-organ-donation-contractors-lobby-against-a-popular-health-care-initiative-while-pocketing-pandemic-relief-loans/)).

<sup>18</sup> *Client Profile: Organ Donation Advocacy Group*, Open Secrets (online at [www.opensecrets.org/federal-lobbying/clients/summary?cycle=2019&id=F318038](http://www.opensecrets.org/federal-lobbying/clients/summary?cycle=2019&id=F318038)).

<sup>19</sup> Pub. L. No: 116-136, §15011.

<sup>20</sup> Letter from Kelly Ranum, President, Association of Organ Procurement Organizations, to The Hon. Alex Azar, Secretary, Department of Health and Human Services (Apr. 30, 2020).

<sup>21</sup> *Heartless: Organ Donation Contractors Lobby Against a Popular Health Care Initiative*, Project on Government Oversight (Oct. 5, 2020) (online at [www.pogo.org/investigation/2020/10/heartless-organ-donation-contractors-lobby-against-a-popular-health-care-initiative-while-pocketing-pandemic-relief-loans/](http://www.pogo.org/investigation/2020/10/heartless-organ-donation-contractors-lobby-against-a-popular-health-care-initiative-while-pocketing-pandemic-relief-loans/)).

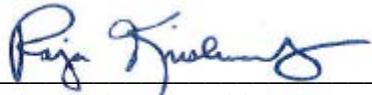
Mr. Steve Miller

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coronavirus pandemic relief, including the Provider Relief Fund and the Paycheck Protection Program.

The Committee on Oversight and Reform is the principal oversight committee of the House of Representatives and has broad authority to investigate “any matter” at “any time” under House Rule X. An attachment to this letter provides additional instructions for responding to the Committee’s request. If you have any questions regarding this request, please contact Subcommittee staff at (202) 225-5051.

Sincerely,



Raja Krishnamoorthi  
Chairman  
Subcommittee on Economic and  
Consumer Policy



Katie Porter  
Member of Congress

Enclosure

cc: The Honorable Michael Cloud, Ranking Member  
Subcommittee on Economic and Consumer Policy