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August 26, 2020

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201

Dear Secretary Azar,

We write today to strongly urge you to quickly issue a strong rule to bring much-needed accountability and oversight to our nation's 58 Organ Procurement Organizations (OPOs) and to the United Network for Organ Sharing (UNOS), the private organization that manages the nation's organ transplant system. As you know, OPOs each have a monopoly under a contract with the federal government for a U.S. region to recover life-saving organs for patients in need. First, we applaud the work you have done to date, including issuing a Notice of Proposed Rule Making on December 17, 2019 and the Executive Order President Trump issued on July 10, 2019 that requires the Department of Health and Human Services (HHS) to "revise Organ Procurement Organization rules and evaluation metrics."

There are serious, widespread problems in our organ transplant system including OPOs self-reporting and grading themselves on their performance. This is one factor that has led to grave consequences. According to the *Associated Press*, out of about 2.8 million deaths in 2018, there were only 10,721 deceased donors whose donations led to just 29,680 transplants. This number could be much higher. A University of Pennsylvania study that examined deaths, donations and health records calculated that a higher-performing system could produce up to 28,000 more donated organs a year. Research from the University of Pennsylvania also found that those self-reported metrics are wildly inflated. The OPO covering central New York state reported a 71% recovery rate between 2012-2014 but the study found that the real rate was around 27%. In north-central California, the reported rate was 82% but the real rate was 28%. This is completely unacceptable as over 1,000 Americans die waiting for an organ transplant every month.

Recent reporting from *Kaiser Health News* revealed "a startling number of life-saving organs are lost or delayed after being shipped on commercial flights, the delays often rendering them unusable" because UNOS uses a "primitive system of phone calls and paper manifests, with no GPS or other electronic tracking." According to HHS itself, OPOs are failing to do their jobs in recovering eligible organs as more than half of all OPOs out of compliance on standard performance measures. And yet all OPOs continue to be given a federal contract decade after decade.

This incompetence has also cost tremendous amounts of taxpayer dollars. As Andy Slavitt, the former head of the *Centers for Medicare and Medicaid Services* and FreedomWorks President Adam Brandon recently noted in a joint op-ed for *USA Today*, “because most patients in need of kidney transplants are placed on dialysis while they are waiting for a kidney to become available, dialysis now costs Medicare than \$35 billion annually — a full 1% of the federal budget. Simply by increasing the number of kidney transplants, however — which is also the best medical outcome for those patients — taxpayers could save up to \$12 billion in just five years through avoided dialysis costs.”

We are disturbed that OPOs are now asking that the proposed accountability measures in this upcoming rule be delayed because of the COVID-19 pandemic. We strongly urge that you issue the rule without delay and that it is not watered down to appease the OPOs. Now is the time for bold action. Simply put, if the worst performing OPOs were held to higher standards and became as high performing as the best OPOs, we would save of thousands of lives every year. We need the new rule to dramatically boost oversight and accountability through independent outcome measures and auditing as well as setting up a process to decertify and replace underperforming OPOs if they do not meet essential standards. We must inject competition into this sector of healthcare – too many lives are on the line.

Thank you for your time and attention to this time-sensitive and critical matter.

Sincerely,



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Member of Congress



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Member of Congress
Co-Chair, Diabetes Caucus



Suzan DelBene
Member of Congress
Co-Chair, Kidney Caucus



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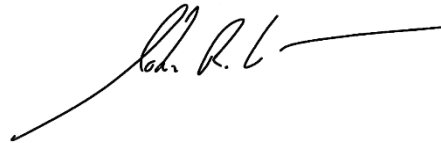
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