



October 9, 2020

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

Re: Administration's oversight of Organ Procurement Organizations

Dear Secretary Azar:

On behalf of Families USA, a leading national, non-partisan voice for health care consumers dedicated to achieving high-quality, affordable health care and improved health for all, I urge you to move quickly to issue a pending rule that would bring much-needed accountability and oversight to our nation's organ procurement and transplant system.

As you know, the country's 58 Organ Procurement Organizations (OPOs) and the private organization that manages our national transplant system (the Organ Procurement and Transplantation Network, operated by UNOS) have been largely left to regulate themselves. As a result, there are serious, widespread, and systemic problems stemming from a lack of transparency and accountability, and every year over 20,000 potentially life-saving organs are wasted despite the wishes of their donors.ⁱ All the while, seriously ill patients linger unnecessarily on transplant waitlists for years, reliant on expensive and unending medical treatments such as kidney dialysis, and over 1,000 people in America die waiting for an organ transplant every month.ⁱⁱ This is unconscionable.

We appreciate the work the Administration has already done to shine a light on this issue, both through the Notice of Proposed Rule Making on December 17, 2019 and the President's Executive Order issued on July 10, 2019 that requires the Department of Health and Human Services (HHS) to "revise Organ Procurement Organization rules and evaluation metrics."ⁱⁱⁱ While the emergence of the coronavirus pandemic may have interrupted immediate plans to issue a final rule, it is critical that this regulation does not continue to fall by the wayside because of COVID-19.

In fact, it is more urgent than ever before that you put into place enforceable and actionable metrics to address OPOs' failures, as their mismanagement amplifies the same underlying health disparities that COVID-19 has exacerbated. Black Americans are three times more likely to suffer from end-stage kidney disease and yet in 2019 Black and Latinx patients received a transplant at almost half the rates as their white counterparts.^{iv} We know that Black and Latinx Americans are three times more likely to contract and twice as likely to die from COVID-19^v, and we have reason to be concerned about the long term health effects of COVID-19 on survivors, including the potential for lasting organ damage. While it is clear that a variety of proactive steps need to be taken to better protect and invest in the health and

wellbeing of people of color in the first place, we can start by taking immediate steps to ensure equal access to organ transplantation when needed, which begins with holding accountable the government contractors responsible for managing organ donation.

The current system is failing families all across America, but you have the opportunity to change that. Organ donors and patients in need deserve to be served by OPOs that are accountable to the highest standards. We urge you to take critical steps to save thousands of lives by issuing a strong and comprehensive rule without delay.

Thank you for your time and attention to this time-sensitive and critical matter. Please contact Jennifer Taylor, Senior Director of Federal Relations at Families USA (jtaylor@familiesusa.org), for further information.

Sincerely,



Frederick Isasi, JD, MPH
Executive Director

ⁱ <https://www.rollcall.com/2020/07/09/dont-let-the-covid-19-crisis-delay-reforms-to-our-organ-transplant-system/>

ⁱⁱ https://www.washingtonpost.com/opinions/many-die-waiting-for-organs-the-trump-administration-could-help/2020/07/31/77e3a102-dfd6-11e9-b199-f638bf2c340f_story.html

ⁱⁱⁱ <https://www.hhs.gov/about/news/2019/12/17/trump-administration-proposes-new-rules-increase-accountability-availability-organ-supply.html>

^{iv} <https://www.rollcall.com/2020/07/09/dont-let-the-covid-19-crisis-delay-reforms-to-our-organ-transplant-system/>

^v <https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-african-americans-cdc-data.html>