



July 6, 2021

**Board of Directors**

Victor J. Reyes, MBA  
Deloitte Consulting LLP  
*Chair*

Donna R. Cryer, JD  
*President & CEO*

Nicholas Austin, JD  
Wells Fargo Bank

Lisa Boyette, MD, PhD  
Curable and Curable Consulting

Dennis R. Cryer, MD, FAHA  
CryerHealth LLC

Gary Deverman, CFRE  
NutriStyle

Ben Goodman  
Mission:Readiness

Monica H. McGurk, MBA  
Kellogg Company

Laurie Mobley  
BRG Communications

Brian Munroe  
Bausch Health Companies Inc.

Lewis R. Roberts, MB, Chb, PhD  
Mayo Clinic

Amita Shukla, MBA  
VitaMita

Amy L. Wright, JD  
Taft, Stettinuss & Hollister

Global Liver Institute  
4323 Westover Place, NW  
Washington, DC 20016

Email: [Info@GlobalLiver.org](mailto:Info@GlobalLiver.org)  
Website: [www.GlobalLiver.org](http://www.GlobalLiver.org)  
Twitter: [@GlobalLiver](https://twitter.com/GlobalLiver)

Executive Office of the President  
The Office of Management and Budget  
725 17th Street, NW  
Washington, DC 20503

**RE: OMB-2021-0005 RFI; Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government**

**The Urgent Need to Reform an Organ Transplantation System rife with health inequities**

To Whom It May Concern,

Equity matters, ethically, scientifically and by law. People of color are 1.5 - 4 times more likely to have conditions leading to kidney and liver failure but less likely to receive transplants.<sup>1</sup>

The reality is that the U.S. organ donation system is broken. This problem is not new; in fact, it's been well-documented for over 20 years by everyone from government agencies to academic institutions to patient groups to private contractors. It is no more evident than its impact on patients and donor families of color through every phase of the process – from getting on the waitlist, to finding a match, to becoming a donor.<sup>2</sup> Both donor families and patients of color who need an organ experience different treatments and a system deeply rooted in inequity.<sup>3</sup>

As a global 501(c)3 nonpartisan nonprofit liver health organization, we are committed to improving the lives of individuals and families impacted by liver disease by promoting innovation, encouraging collaboration, and scaling optimal approaches to help eradicate liver diseases. We are driven by the needs and perspectives of liver health patients and donor families of color, too many of which are impacted by history and the current state of discrimination limiting equitable access to transplant care. In response, we are united in our conviction that with vigorous efforts to pursue every potential donor and as many of the core organs as possible - heart, lung, liver, kidney, and intestine - including single organ

<sup>1</sup> <https://bloomworks.digital/organdonationreform/Inequity>

<sup>2</sup> This article follows a Black patient's journey from listing to transplant. [“Good for Harvest, Bad for Planting.”](#) Health Affairs, 2007.

<sup>3</sup> [“Comparison of black and white families’ experiences and perceptions regarding organ donation requests.”](#) Crit Care Med, 2003

donors, marginal/extended criteria donors, and older donors, thousands more organs will be available for transplantation.

More than 13,000 patients with liver disease are waiting for transplants, a majority of which are people of color. And yet, ethnic minorities comprise approximately 30% of all adult liver transplantations performed annually.<sup>4</sup> This is why we applaud the Office of Management and Budget for recognizing the value of collaboration and working collectively with the public health community to address the barriers that prevent people of color from accessing essential transplant care.

In response to the agency's request for information on approaches, methods, tools, and data that might be needed to further advance the administration's mission to achieve equity, we believe that there are a few critical steps that can be taken to begin to positively address health inequities within the organ donation system.

### **We must hold Organ Procurement Organizations (OPO) fully accountable.**

It is critical to urgently advance the U.S. Department of Health and Human Services' (HHS) lifesaving, pro-patient regulations titled "Medicare and Medicaid Programs; Organ Procurement Organizations Conditions for Coverage: Revisions to the Outcome Measure Requirements for Organ Procurement Organizations; Final rule."<sup>5</sup> This rule could save more than 7,000 organs a year.<sup>6</sup> It will install basic transparency and accountability measures for OPOs. Furthermore, it will ensure safe, high-quality care that puts patients first by: supporting higher donation rates; reducing discarded but viable organs; and modernizing organ recovery and transplantation. Most importantly, this measure will incentivize OPOs to invest in serving their entire community, which includes hiring more diverse staff and investing more time and resources to develop relationships with underserved populations and the hospitals that serve them.

The OPO final rule is a critical first step toward reducing waiting lists that are much longer than necessary. But as no OPO will currently face decertification until 2026, we ask OMB to do all that it can to usher in urgent accountability sooner. COVID-19 - and its devastating, inequitable effects - will only make things worse, creating more patients with organ failure.

### **We must invest in culturally appropriate education and training.**

Multiple studies have shown that Organ Procurement Organization staff are less likely to approach families of color for consent,<sup>7</sup> have less frequent conversations, spend less time in those conversations, and demonstrate bias in assumptions of who would be eligible or willing to donate.<sup>8 9</sup> Failure to invest resources in culturally appropriate education, and staff to have these most difficult conversations with families result in unnecessarily low awareness and trust levels.

---

<sup>4</sup> Kemmer N. (2011). Ethnic disparities in liver transplantation. *Gastroenterology & hepatology*, 7(5), 302–307.

<sup>5</sup> <https://www.cms.gov/files/document/112020-opo-final-rule-cms-3380-f.pdf>

<sup>6</sup> <https://www.hhs.gov/about/news/2020/11/20/hhs-secretary-azar-statement-final-rule-increase-access-lif esaving-organs.html>

<sup>7</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1508526/>

<sup>8</sup> [https://journals.lww.com/ccmjournal/Abstract/2003/01000/Comparison\\_of\\_black\\_and\\_white\\_families\\_.23.aspx](https://journals.lww.com/ccmjournal/Abstract/2003/01000/Comparison_of_black_and_white_families_.23.aspx)

<sup>9</sup> <https://link.springer.com/article/10.1007/s40615-020-00806-7>

We must invest in a strategic plan that prioritizes educating, training, expanding, and collaborating with racial and ethnic minorities, rural communities, and special donor populations such as seniors and children.

### **We need an Office of Organ Policy.**

We need an Office of Organ Policy to elevate equity in donation, recovery, and transplantation and ensure it is an integral part of all activities. Also this office would ensure that efforts across the U.S. Department of Health and Human Services (HHS) in disease prevention, donation awareness, waitlist policies, incentives to transplant, and survivorship are brought together in an efficient fashion.

Most importantly this office can develop targeted strategies that respond to the health disparities in the organ transplant system. Strategies focused on racial obstacles to getting on the waitlist, fewer medically suitable organs available for patients of color, potential donors of color being less likely to be referred, failing to get proper authorization, and finding a correct donor/organ match. This office would unite a community too often distracted and divided by liver allocation rules that just shift disadvantages from patient type to patient type.

### **Conclusion**

Thank you for your leadership and commitment to solutions that address health inequities within the organ donation system. Thank you for your persistence in getting real answers, and your attention to the voices and experiences of patients and donor families of color.

If you have any questions, please don't hesitate to reach out to Global Liver Institute's Policy Director, Andrew Scott, at [ascott@globalliver.org](mailto:ascott@globalliver.org) or 831-246-1586.

With appreciation and respect,

A handwritten signature in black ink that reads "Donna R. Cryer". The signature is written in a cursive, flowing style.

Donna R. Cryer, JD  
President & CEO  
Global Liver Institute