



Response: Request for Comment on organ donation and transplantation

Chiquita Brooks-LaSure

January 31, 2022

Administrator

Centers for Medicare & Medicaid Services,

Department of Health and Human Services,

Attention: CMS-3409-NC,

Mail Stop C4-26-05,

7500 Security Boulevard, Baltimore, MD 21244-1850

Dear Administrator Brooks-LaSure:

On behalf of the Transplant Community Coalition, I would like to thank you for the opportunity to provide feedback and insight on the Centers for Medicare & Medicaid Services' (CMS) Request for Comment on organ donation and transplantation.

The Transplant Community Coalition is comprised of leading advocacy organizations dedicated to addressing the most pressing unmet needs of the transplant community at each stage in their journey. Our four core pillars of work center around supporting those awaiting transplant, engaging donor families, increasing minority donor awareness, and guiding transplant recipients. Our members include:

- American Transplant Foundation
- Chris Klug Foundation
- Donate Life Coalition of Michigan
- The John Brockington Foundation
- Keep Swimming Foundation
- Michigan Donor Family Council
- NJ Sharing Network
- Transplant Life Foundation

Our comments address several of the questions brought forth in the request for information and outline possible solutions to specifically address the need for increased access, education, and equity within the transplant ecosystem.



Response: Request for Comment on organ donation and transplantation

Conduct Dialysis & OPO Systems Reviews

To level set and understand the state of the ecosystem it is imperative to begin with a review of the current systems in place. We recommend the following actions:

Initiation of a complete study of the dialysis industry in the United States with participation of practitioners, patient advocacy groups, federal regulators, and legislators with the objective of assessing:

- Current levels of care
- Patients' access to treatment
- Federal and state financial support
- Oversight and remediation
- Continued review of practices and assessment of the Organ Procurement Industry
 - In particular, consideration must be given to each OPO's standing in their community. Public trust is earned and often over a long period of time. The OPO's investment in, and engagement with the public education piece of transplantation must be considered. Trust will not seamlessly transfer to another organization in the unfortunate case of a reassigned designated service area. If the public trust suffers, the transplant community will suffer.
- Evaluation and correction of deficiencies in quality and timing of retrieval and distribution of organs

Throughout this review, we recommended highlighting and promoting procedures and practices that demonstrate outstanding performance.

Elevate Advocacy Organization Programming

Transplant advocacy organizations are intimately familiar with the needs of the community they serve and have developed effective programming to help improve education, access, and equity. To aid these processes already in place, we recommend instituting federal and state funding to these organizations to bolster essential programs and reach the communities in most need.



Response: Request for Comment on organ donation and transplantation

Expand Education

In addition to the financial support of educational programs already instituted by advocacy organizations, we recommend the development of the following to expand education:

- Development of a formal education program that will nationalize successful programs to promote and highlight organ, eye, and tissue donation. Pockets of success are evident, but not widely promoted to gain additional success on a national level.
- Addition of “transplant related” modules for medical schools and nursing programs to educate and encourage future medical staff to consider transplant as a field of practice.

Improve Equity

Working to establish a more equitable transplant ecosystem should be a top priority of CMS. We recommend the following as a starting point:

- Provide federal funding to support additional transplant programs for hospitals in areas that treat and care for people of color.
- Provide funding to the Community Relations Department of OPOs to build trust and organ donation awareness in historically underserved populations and communities via local community based organizations such as places of worship, barber shops and salons, YMCAs etc.

Increase Access

Access and equity are deeply intertwined. There can be no equity without fair access.

While there are many areas of access to tackle, there are two in particular we would like to specifically highlight:

- Access to affordable housing and covering expenses during patient evaluation, pre-processing and post-processing.
 - Increased access can be achieved through providing financial support to advocacy organizations dedicated to supporting affordable housing and coverage of expenses during the transplant process such as Transplant House of West Michigan and Second Chance at Life.
- Access to affordable anti-rejection medicine (and all associated medicines) needs to be made available to all recipients for the life of the recipient. Increased access has been established for kidney recipients, but these same changes need to be made for all recipients. Access to care is also as vital as access to treatment.



Response: Request for Comment on organ donation and transplantation

The Importance of Living Donation

Living Donation is essential to the present and future of transplantation. Collaborative efforts to increase living donation will have a direct impact on lowering the number of patients waiting for a kidney or liver transplant.

Awareness and education are critical drivers in increasing numbers. Tactics to consider include:

- Establishment of a separate national organization to create and provide oversight of a growing and very much needed "living donation" practice.
- Funding to drive educational programming through advocacy organizations focused on living donation.

Thank you again for the opportunity to comment on CMS' RFI for Transplant System Modernization.

Sincerely,

A handwritten signature in blue ink that reads "Bill Ryan". The signature is fluid and cursive, with the first and last names clearly legible.

Bill Ryan

Transplant Community Coalition Lead