



March 12, 2019

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The Honorable Seema Verma
Administrator
Centers for Medicare & Medicaid Services
200 Independence Avenue S.W.
Washington, DC 20201
Seema.Verma@cms.hhs.gov

Dear Administrator Verma,

There are currently 115,000 people on the waiting list for organ transplants in the United States, and hundreds of thousands more who are likely to need transplants in the near future. For these patients, organ transplant represents the best – and often only – chance to live.

Recent *Washington Post* investigative reports detailed gross inefficiency in the Organ Procurement Organization (OPO) industry. Specifically:

“A [Washington Post] analysis of 2.7 million death records from 2016 found that as many as 27,000 people met established criteria for organ donation — more than twice the number of actual donors that year. At its current average of about three organs per donor, the industry could have produced more than 75,000 organs for transplant that year — enough to put the nation on pace to wipe out the waiting lists within a few years.”

Additionally, the *Washington Post* reporting indicates that a key barrier to systems improvement is a flawed metric that is used to evaluate OPO performance.

“A longtime Department of Health and Human Services official... said that a key problem was CMS’s performance measures, which still rely on self-reported data and are not rigorous enough to be used to hold [OPOs] accountable.”

Six years ago, one of the nation's largest OPOs told the Office of Management and Budget that "the data that OPOs submit to CMS in connection with the outcome measures is self-reported and unaudited" and the OPO trade association acknowledged that the "accuracy and consistency of data cannot be assured."

As patients for whom access to transplant is literally a life-and-death issue, it is both encouraging to know that our cure already exists and devastating to understand that thousands of patients die each year as a result of ineffective regulations impeding access to it.

We ask you to take strong and immediate action to remedy this problem.

Specifically, we ask that you change the metrics by which OPOs are evaluated to a new metric that is verifiable and not open to self-reported interpretation, so that this Administration may become the first to enable meaningful OPO performance accountability. Our lives depend on it.

With appreciation and respect,

Patient Advocacy Organizations:

- American Association of Kidney Patients
- American Society of Nephrology
- Cholangiocarcinoma Foundation
- Fatty Liver Foundation
- Global Liver Institute
- Liver Education Advocacy and Prevention Services
- Renal Physicians Association

Individual Patients & Advocates:

- Kara Brumley
- Michael Pritchett
- Eric Brumley
- Thomas Cooper Henson
- Laura Johnson
- James White
- Amanda Washek
- Barbara Lundberg
- Conor Hayden
- Elise Nicole Wells
- Sharon Meade
- Natasha Lapeyre
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Andrea Johnson
Steven West
William Boyd
Jennifer Cross
Holly Fisher Britt
Gloria Jean Brissette
Alireza Memari
Patrick Stanton
Stacy Lynn Seifert
Anonymous