

From: [Jim Urtel](#)
To: [HRSA Paperwork](#)
Subject: [EXTERNAL] Potential_SPAM:Process Data for Organ Procurement and Transplantation Network
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Hello, My name is James Urtel Jr. and I support the proposed HRSA data collection because it will address disparities in transplant access, improve transparency, and enhance donor management practices. This is an important step toward saving more lives and ensuring equitable care for all patients. I have been a kidney disease patient for 13 long years now and can vouch for the system needing some changes.

In 2012 I went to the ER thinking I had a bad chest cold or something as I was having trouble breathing when laying down. Much to my surprise, I was diagnosed with End stage kidney disease and 8 days later started kidney dialysis. Untreated Sleep Apnea over time had caused high blood pressure which led to the failure. I was put on the kidney transplant list at UPMC in Rochester, NY and told my wait time would be around 4-5 years. I was told how great of a candidate for transplant I was because I had no other ailments such as diabetes, high cholesterol etc. It turned out to be 8 long years before I finally got the call in 2020 for transplant. Unfortunately, the kidney used was not pre-screened properly and had 40-50% scar tissue in it at the time of use which was confirmed by a biopsy 2 ½ months later. The best eGFR I had after transplant was 26 and I was right back into stage 4 kidney failure. Much to my doctor`s surprise, I am still going with this kidney but am back on the list for a new transplant this time at EMMC in Buffalo, NY. I am working with a Living donor group this time trying to find a donor before having to go back on dialysis which I don`t know if I could do again.

My main concerns are 1. how can a transplant center have a patient wait for 8 years who was told was an excellent candidate and obviously was considering I have kept going through strong will, diet and exercise and still considered a great candidate for transplant If 8 years wasn`t enough, they used a kidney that was 50% damaged at the time of use and nothing was done for me other than best wishes from them. 2. Why is my 8 years of waitlist time gone and I am forced to start over again after the Transplant Center made the mistake? The average lifespan on dialysis is only 5-7 years and UPMC pushed me past that and then used a bad kidney and I just have to hopefully live with this!

After living through what I have, there has to be some changes made to the system. In truth, time on the list doesn`t matter as they still pick and choose who gets the kidney and the patient never knows nothing. Even the Living donor process is a bit ridiculous as far as how long it takes for a potential donor to get through the process and be approved

to donate.

I hope that something can be done to help in all aspects of the kidney transplant process. Thank you

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