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To: [HRSA Paperwork](#)
Subject: [EXTERNAL] Process Data for Organ Procurement and Transplantation Network.
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My world was turned inside out when my doctor told me I needed a liver transplant or I would die. I had so many questions but wasn't getting the answers I was seeking. I found out that I wasn't alone as thousands of patients were also facing this uncertainty.

The Organ Procurement and Transplantation Network (OPTN) plays a very important role in thousands of lives of patients awaiting a lifesaving transplant. However, the lack of comprehensive and accessible data is lacking. This creates barriers to education, transparency and empowerment for patients. Action is needed now.

As a liver and kidney pre-transplant myself, I know first hand the challenges of trying to navigate the transplant system. For those of us enduring dialysis or living in fear as our organs fail, knowledge is power. We deserve accurate, actionable information to make informed decisions about our care.

Limited data collected by OPTN as well as data published by the Scientific Registry of Transplant Recipients (SRTR), often leaves patients in the dark.

Without better data collection, many lifesaving insights about transplantation will remain hidden.

The last major update to OPTN's database was in 2014, leaving a decade-long gap in critical advancements. Patients are calling for updated tools to ensure equitable and fair access to transplantation.

Without this updated information how can patients make informed decisions about their care?

Why isn't data on waitlist times and organ allocation outcomes readily available?

Every patient deserves a fair chance at life.

Thank you,

Lois Sharp

Pre Live and Kidney transplant patient

Pre Liver and Kidney Transplant patient

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