



Service to those affected by chronic kidney disease

Lori Hartwell  
*Founder/President*

September 12, 2023

Wendy Rodgers, M.Ed, MPH  
*Chairman of the Board*

Dear Health and Human Services, The Honorable Xavier Becerra Secretary  
U.S. Department of Health and Human Services 200 Independence Avenue SW  
Washington, DC 20201

Lana Kacherova, RN  
*Treasurer*

Dear Secretary Becerra:

Joanna Galeas Lee  
*Secretary*

### **Improving the OPTN System for people in need of a life-saving organ**

#### **Board Members:**

Lubna Akbany, RD  
Kathleen Baldwin, PhD  
Kristen Cisneros, RN  
Marlene De Vera, RN  
Joanna Galeas Lee

We would like to express our expectations for the new OPTN (Organ Procurement and Transplantation Network) contractors to address and improve communication with individuals who have been approved for the transplant list. It is crucial that those on the transplant list are promptly notified on their status through modern technologies such as text messaging or other current communication platforms. This would ensure that patients receive timely updates and relevant information regarding their status and potential transplant opportunities.

Lori Hartwell  
Dean Hartwell, JD  
Jill Heydorff  
Lesley Holden, RN  
Lana Kacherova, RN  
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Rafael Villicana, MD  
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CNN

It is quite disheartening to learn about the large number of people waiting for a kidney transplant. We were surprised to learn that over 40 percent of people on the kidney transplant list are **inactive**. We have not found a study that explains the cause of this large percentage of people who are inactive. Is the patient too sick, needs a test/visit or the transplant hospital didn't receive the necessary blood work etc.? It is indeed crucial for patients to have access to this important information and the necessary time to complete medical tests without delay, so they remain active on the list. Especially, when it comes to keeping all the necessary reports to emphasize your well-being are up to date from other medical providers. Additionally, regular updates can alleviate stress, uncertainty, and the feeling of being forgotten, offering reassurance that their needs are being acknowledged and prioritized.

This will help ensure that people do not miss out on potential opportunities for a suitable transplant. This will also help with the waste of organs if more people are active on the wait list and ready for transplant the more opportunities to transplant life-saving organs. [LaQuayia Goldring's testimony](#) to the Senate Finance Committee on July 20, 2023, emphasizes the great need for this as she missed a chance at a kidney due to a labeled inactive and she was not aware of this.

An illness is too demanding when you don't have hope!  
– Lori Hartwell, RSN Founder and President

## Renal Support Network

**ASK:** Require a standardized approach to communication and updates for medical clearances required for people on waitlist helps promote effective healthcare delivery, enhances patient experience, and ultimately contributes to improved transplant outcomes. By establishing systematic communication channels, people who are on the waitlist have plenty of time to see the specialist to address any concern, so they are not placed inactive while they wait for the appointment of the specialists.

There is great concern regarding the validity of contact information for people on the OPTN transplant platform. It has been stated that 20% of individuals could not be reached due to incorrect contact details. Steps should be taken to ensure the accuracy of data to reach patients. It is suggested that authentication measures be implemented to verify that patients are receiving the necessary communication, such as text messages or the modern forms of communication. This is a common practice, as most individuals have cellphones that can access their medical records portals. Incorrect data entry or clerical errors leads to loss of deceased lifesaving organs and loss of lives. Improving data management processes is crucial in this case.

**ASK:** Require technology that communicates effectively and validates contact information with the people who are wait listed.

We have developed a transplant dashboard on our website using information compiled from the OPTN data source. We noticed that the UNOS website is complicated for patients and families to comprehend, making it difficult for them to understand the information they are viewing. It is crucial that the data presented to the lay person is easily comprehensible. We believe that it should not be so complex that only statisticians or researchers can understand it.

To address this issue, we extracted the simpler yet significant facts from the website and incorporated the data into our transplant dashboard. The creation of this dashboard required the dedication of numerous hours, generously donated by Salesforce. One of our members who work at Sales Force, who selflessly donated a kidney to their best friend, passionately led this project as he himself could not easily navigate the UNOS website for the info he wanted to know.

**ASK:** It is crucial that the data presented is meaningful and easily comprehensible to patients and families.

If a transplant center were to reject or decline a patient based on their specific criteria, it is important that the individual be informed of their right to seek a second opinion. Providing patients with the option to seek alternative opinions and explore other potential transplant centers can be lifesaving.

Allowing patients to be proactive in their pursuit of transplantation is essential, as they often are unable to navigate the complex healthcare system without access to relevant information. By ensuring a transparent and patient-centric approach, we can empower individuals to make informed decisions about their healthcare and improve their overall transplant experience.

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**ASK:** Since transplant centers have different criterion to accept a person into their program it is important to provide the patient information of why they were denied for transplant and that they can seek another opinion from another transplant center if they don't agree with it.

The system needs to develop an effective transportation infrastructure to transport the gift of life safely and rapidly from donors to recipients. Established protocols and best practices to ensure timely delivery of organs, maintaining their viability for transplant. Utilize advanced information technology systems to enable real-time tracking and monitoring of organ transportation. By implementing these systems in a comprehensive and coordinated manner, it is possible to track and manage organs effectively, providing life-saving transplants to those in need while maintaining the integrity and fairness of the process.

**ASK:** Require information technology solutions using GPS tracking, barcoding, and other technologies to ensure accurate and secure organ information and location data. This will help provide visibility and traceability throughout the organ transplantation process and prevent loss or delay of the gift of life.

In conclusion, a transplant is not a cure and a form of treatment that requires daily medication and follow up test and care. Post-transplant follow-up care and connecting with peer support groups are essential for people who undergo transplantation. These crucial aspects of care provide much more than just physical well-being; they empower transplant recipients to become advocates for their own health and not end up back on the list. By actively engaging in follow-up appointments and participating in support communities, individuals can gain invaluable knowledge, emotional support, and a sense of belonging. This enables them to take charge of their illness and advocate for themselves with confidence. Thus, embracing follow-up care and peer support is not only vital for continued health but also for empowering transplant recipients in their journey towards a fulfilling and purposeful life and to maintain the gift of life.

We also believe it is important to get patient, family, medical professionals' perspective and determine on what data sets are to be presented on the Health Resources & Services Administration [dashboard](#) to the public. Validate that the data given is easy to understand for the lay person. We would welcome the chance to be part of this focus group.

Ensuring effective communication and providing regular updates to individuals on the transplant waiting list is of utmost importance. These practices will foster's transparency, trust, and patient satisfaction, as individuals feel empowered and involved in their healthcare journey.

Thank you for considering our suggestions. We believe that by incorporating these changes, we can significantly enhance the transplantation process and ultimately improve patient outcomes and let them live the life they were meant to live.

## Renal Support Network

Please let me know if you have any questions or need additional information.

Warmest Regards,



Lori Hartwell,  
President & Founder

RE: <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/>

**Cc: Sean McCluskie** Chief of Staff **Department of Health and Human Services**