N.C.O.T.S.

norcaltransplantsupport.org

Next Meeting: Sunday, December 8 1 pm – 3:00



<u>Click This</u>

Zoom Link to Join



December 8, 2024 Monthly Newsletter



Organ transplants & HIV Agenda



Continuous Distribution Physical Meetings



Smart Match



Organ Transplant Laws

"WHEN YOU DONATE AN ORGAN YOU ARE GIVING SOMEONE A TOMORROW."
~~~Mom~~~

Northern California Organ Transplant Support

## New Biden-Harris Policy Expands Access to Life-Saving Organs for People with HIV

Final Rule Removes Clinical Research Requirements for Kidney and Liver Transplants from Donors with HIV

Recently the U.S. Department of Health and Human Services (HHS) announced a <u>final rule</u> that will expand access to kidney and liver transplants for people with HIV by removing clinical research requirements for these transplants. This action marks a significant step forward in increasing the availability of life-saving organs for all patients regardless of their HIV status while continuing to reduce barriers and stigma for people with HIV.

The final rule, which further implements the HIV Organ Policy Equity (HOPE) Act, removes the clinical research and institutional review board (IRB) approval requirements for kidney and liver transplants between donors with HIV and recipients with HIV. This change is based on research demonstrating the safety and effectiveness of kidney and liver transplants between donors and recipients with HIV.

"We continue to do everything in our power to increase access to life-saving organs while addressing health inequities faced by people with HIV," said HHS Secretary Xavier Becerra. "This rule removes unnecessary barriers to kidney and liver transplants, expanding the organ donor pool and improving outcomes for transplant recipients with HIV. This evidence-based policy update demonstrates our commitment to ensuring all Americans have access to the care they need."

"Research shows that kidney and liver transplants between donors and recipients with HIV can be performed safely and effectively," Assistant Secretary for Health Admiral Rachel L. Levine, M.D., added. "This policy change reflects our commitment to following the evidence and updating our approaches as we learn more. By removing research requirements where they are no longer needed, we can help more people with HIV access life-saving transplants." - Health and Human Services Administration,@ www.hrsa.gov > about > news; see also, www.hhs.gov > news > 2024/09/19

#### **AGENDA**

- Welcome and Introductions
- Angelika, of Sierra Donor Services
- Our Social Media Presence
- Future physical Meetings
- Open Discussion
- ❖ Adjournment



### CONTINUOUS DISTRIBUTION How effective is this new policy?



The "Continuous Distribution" system is working well, according to UNOS. The lungs were the first organ to fully transition to this new framework. Kidneys are scheduled next for continuous distribution. Other organs will follow. Continuous Distribution is a fairer and more flexible approach to matching organs with patients. The goal is to get the right organ to the right patient at the right time.

According to recent updates from UNOS, the continuous distribution policy for organ allocation, currently implemented for lung transplants, is working well. Evidence suggests continuous Distribution will improve access to transplants for the most medically urgent patients, potentially reducing deaths on the waiting list. Further work is underway to transition other organ types to this framework, with kidneys and pancreas being considered next.

Key points about the continuous distribution policy:

#### •How it works:

•Instead of placing patients in categories based on factors like blood type, the system uses a composite score that takes into account multiple variables like medical urgency, candidate biology, and organ compatibility, creating a more nuanced ranking system, more accurately reflecting the true conditions of these recipients in waiting.

#### •Benefits:

•This approach aims to eliminate the "hard boundaries" of previous systems, allowing for a more equitable distribution of organs by considering all factors simultaneously, potentially leading to better matches for patients and decreased wait times.

#### •Implementation progress:

•The lung allocation policy has been transitioned to continuous distribution, with a new "lung Composite Allocation Score (CAS)" used to rank candidates.

#### •Future plans:

•UNOS is actively working to expand continuous distribution to other organ types, with the kidney and pancreas allocation policies currently under development.

### ~~~ UNOS, Smart Match and Artificial Intelligence ~~~ Optimizing Organ Recipients to Donors

UNOS is using artificial intelligence (AI) to optimize the matching of organ donors to recipients. They call it *Smart Match. This has emerged as a pivotal advancement, significantly improving organ allocation processes. Starting with lungs, they are reaching for the best possible outcomes by considering compatibility factors beyond traditional matching criteria, potentially leading to:* 

- 1. better utilization of available organs
- 2. less organ wastage
- 3. reduced waitlist mortality

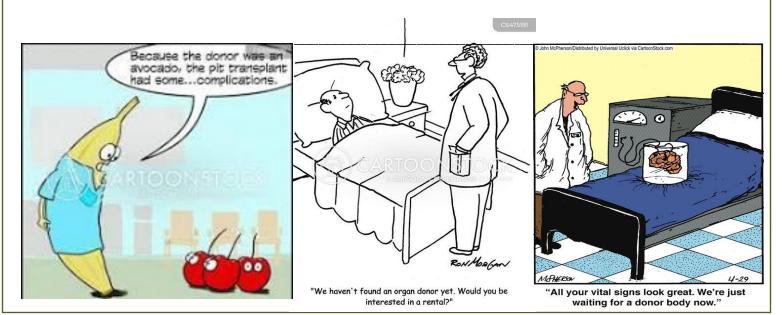
They are also hoping this new organ matching paradigm will lower costs, reduce post transplant rejection and reduce or eliminate many other medical issues. In tests conducted over the past two years, Smart Match is already outperforming the role performed by the MELD system when it is used as a predictive model of damage to the liver, adopted in the US in 2002.

As a group I think we need to find out how Smart Match is going to be affecting waitlist positioning. Lives depend on it.



### **Sierra Donor Services**

Looking for motivated Ambassadors to help them get the word out! Give them a call!





### **Organ Transplantation Laws**



There are many laws on the books affecting organ transplantation. Some have been in committee for too long. We will continue to list laws of interest. If anyone has knowledge of other laws we should know about, please let us know so we can add to our list. Thanks-BRB @ bob\_bilyeu@yahoo.com

- HR 2544: 118th Congress (2023-2024); This bill was called the Securing the US Organ Procurement and Transplantation Network Act. It was passed and signed into public law on 09/22//2023. It expressly authorizes HRSA to award multiple grants, contracts or cooperative agreements to support the operation of the network. It eliminates a cap on funding available for supporting the network. It is now public law 118-14.
- HR 1126: 118th Congress (2023-2024); This bill was called the HOPE Act.
- HR 4362: 118th Congress (2023-2024); Saving Organs One Flight at a Time, introduced in House on 06/23/2023. This bill requires air carriers to transport human organs for transplant above wing (i.e., in the cabin of an aircraft). Among other things, the regulations must include consideration for air control outages, a protocol for a person to accompany organs and a standardized process for commercial air carriers to accept, handle, and manage organs in transit. Referred to subcommittee on Aviation. As of 08/05/2024 it is still in subcommittee on Aviation. It has been there quite a while.
- HR 4343: 118<sup>th</sup> Congress (2023-2024); The Organ Donation Clarification Act amends the National Organ Transplantation Act (NOTA) Introduced on 06-23-2023 by Doris Matsui (D) CA; It provides incentives to encourage donation, calls for reimbursing certain organ transplantation costs; intended to increase organ donation referred to Subcommittee on Health. As of 08/06/2024 this bill is still in the subcommittee on Health
- S1384: 118th Congress (2023-2024); Living Donor Protection Act prohibits certain insurance carriers from discriminating against living organ donors and provides other protections, allows use of FMLA time away from work to recover from organ donation, prevents in the property of the p

Advocates in Michigan are pushing for new legislation to alleviate the financial burden on living organ donors, as the statefaces a critical shortage. According to Gift of Life Michigan, around 2,000 residents are awaiting akidney while 200 are in need of a liver. To address this issue, state legislators have introduced the "Live Organ Donation Tax Credit" bill, which aims to provide up to \$10,000 to cover expenses such as time off work, childcare, and post-surgery care. If passed, this initiative could significantly ease the decision-making process for potential donors and increase the likelihood of saving more lives. Wells O'Brien with Gift of Life emphasized that the proposed bill is designed to ease the financial burden associated with being a living organ donor, making it a more viable option for many potential donors. The tax credit aims address the severe shortage of living organ donors in the state.



### Let's Stay Connected!



| 2024 Leadership Team |               |                                      |
|----------------------|---------------|--------------------------------------|
| Role                 | Name          | eMail                                |
| President            | Jim Deyo      | jdeyo@att.net                        |
| Vice-President       | Spencer Baker | Srbaker98@yahoo.com                  |
| Secretary            | TBD           |                                      |
| Treasurer            | TBD           |                                      |
| Newsletter           | Bob Bilyeu    | Bob Bilyeu@yahoo.com<br>916-675-2721 |



Editor's Note: If there are topics you'd like us to explore let Bob Bilyeu know.



### **Check Out Our Website!**

https://norcaltransplantsupport.org

Let us Know
What you Think!

### **Important Links**



- American Liver Foundation
- Donate Life California
- Sierra Donor Services
- United Network for Organ Sharing

### 2025 Mtg Dates

Jaunary 12 February 9 March 9 April 13 May 18 June 8 July 13 August 10

September 14 October 12 November 9 December 14

