

N.C.O.T.S.

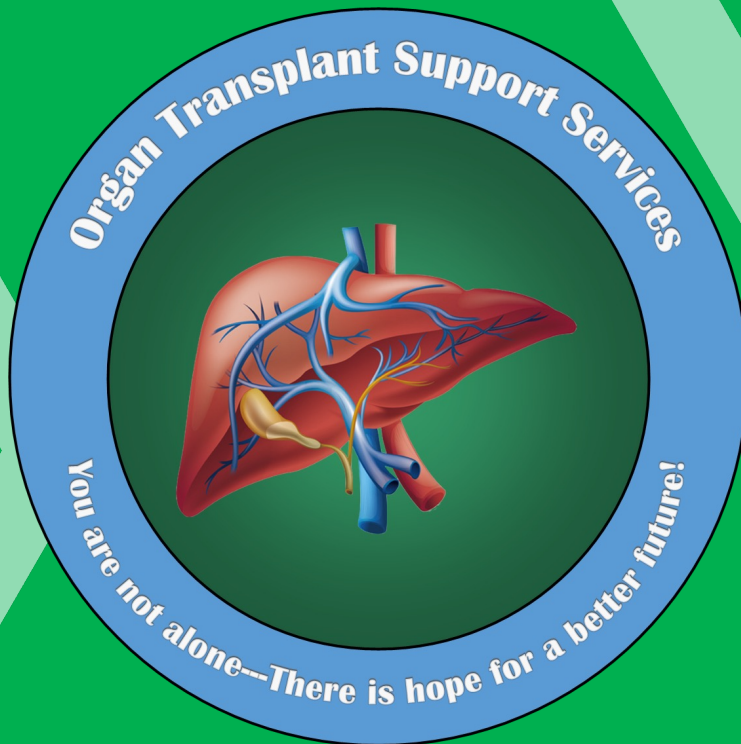
norcaltransplantsupport.org

Next Meeting:
Sunday, July 14th
1 pm – 3:00



[Click This Zoom](#)

[Link to Join](#)



Monthly Newsletter

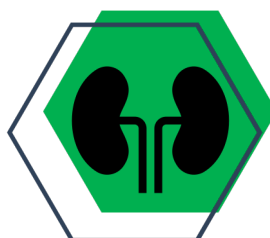
July 2024



JULY AGENDA



Transplant
Tolerance



UNOS NEWS



LAWS ENACTED &
LEGISLATION BEING
CONSIDERED

"We are the ones we've been waiting for; we are the change we seek."

- Barack Obama.



Northern California Organ Transplant Support Group

Established 1991



"If you're not failing every now
and again, it's a sign you're not
doing anything very
innovative." —
~~~Woody Allen



## AGENDA

- ❖ Welcome and Introductions
- ❖ Transplantation Articles on tolerance-conscious surgery
- ❖ Living Donor Study
- ❖ Open Discussion
- ❖ Ambassador Program
- ❖ Adjournment

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## Changes Coming for Immuno-Suppressants

Wouldn't it be nice to go to sleep at night and not have to spend a moment trying to remember if you had taken your immuno-suppressants or how much damage those immuno-suppressants are doing to you? Your higher-than-normal blood pressure, that 'minor' heart palpitation your doctor once told you about that is now being called afib, mental fogginess, those little things doctors say immuno-suppressants may cause would be nice to be out of your life, wouldn't they?

Well, wake up! Drug makers will continue to make these drugs for the foreseeable future, but just over the horizon, things are changing. Last August Massachusetts General Hospital (MGH) opened a first of its kind kidney transplant facility focusing on kidney transplants that require no immuno-suppressants. The process involves injection of specific kidney stem cells of the donor into the recipient. There are hurdles and protocols to adjust, and trials yet to overcome, but the future seems bright. On March 16 this year the first genetically-edited kidney of a pig was transplanted into Richard Slayman, 62, who survived two months before passing of unrelated causes (May 12, 2024). Because of the non-kidney cause of death Xeno transplantation of kidneys seems a good likelihood eventually. Adding to the field of knowledge recently a Mayo Clinic trial advanced the science by following and monitoring 19 volunteer kidney transplant recipients who were injected with specific adult kidney stem cells of their donors. The protocol then required the injection be performed within 2 hours of transplant. After 3 years 16 of the 19 volunteers are immuno-suppressant free. Now UCLA Health is announcing they are the first organization to offer 'retro' immuno-suppressant therapy, delivering donor stem-cells more than a year after transplant. The team at UCLA uses donor stem cells and radiation therapy to help your immune system accept a transplanted kidney. This approach, called immune tolerance or immuno-suppression-free protocol, allows your body to accept the donor organ as its own. They deliver a stem cell infusion immediately following a kidney transplant (simultaneous immune tolerance) or months to years after a transplant (retroactive immune tolerance). Retroactive immune tolerance is a promising new approach available only at UCLA Health. So organ tolerance without immuno-suppressants is possible but only for certain kidney transplants right now.

**Organ Transplant Tolerance is still some distance from us, but getting Closer**

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## Remaining mtg Dates

July 14  
August 11  
September 8  
October 13  
November 10  
December 8



# United Network for Organ Sharing performance in 2023

## 2023 | Organ donors save record number of lives

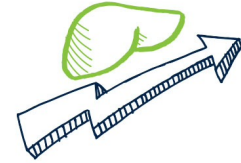


More than  
**10,000**  
Black transplant  
recipients\*

Exceeded

**46,000**

lifesaving transplants total\*



More than  
**10,000**  
liver transplants\*

\*Based on OPTN data as of Jan. 10, 2024.  
Data subject to change based on future data submission or correction

**OPTN** Organ Procurement & Transplantation Network

People who need a lifesaving organ transplant: **103,871**  
Of those, **58,394** people are on the active waiting list.

*All data as of 6-12-24*

2023 donors, deceased and living. -- **23,286**

*January – December 2023*

2023 transplants -- **46,630**

*January – December 2023*

Deceased donors in 2023- **16,386**

living donor transplants in 2023: More than **6,900**

While most living donors provide a kidney for transplant,  
an increasing number of people donate a segment of their liver.

Even with the continued increase in deceased donation,  
the need for organ donors is immense.

Ask a friend to sign up





# TRANSPLANT NEWS!

## A Revolutionary new application of perfusion of organs for Transplant

Dr. Marty Sellers of Tennessee Donor Services and his organ retrieval team are flying to Chattanooga to recover a liver and two kidneys from an organ donor. "We're doing an NRP recovery," says Sellers, referring to normothermic perfusion, a new kind of organ retrieval procedure Sellers calls "revolutionary." "It replenishes the oxygen deprivation that the organs incur during the dying process," says Sellers. "If we recover the organ and put it on ice in an oxygen-deprived state, it's not as healthy when it gets into the recipient. And this way, it's actually recovered in a healthier state so that when it does get to the recipient it's more likely to work."

The NRP innovation produces more, high-quality livers, kidneys, and hearts that could help alleviate the chronic shortage of organs. More than 100,000 people are waiting on waiting lists for organs, most for kidneys, and 17 are estimated to die every day because the number of available organs hasn't been able to keep pace with the demand.

About half of the nation's 56 organ procurement organizations have already started using NRP and more are planning to start soon, according to the Association of Organ Procurement Organization. "It's a very powerful strategy for reducing the organ shortage and helping improve outcomes," says Brandon Parent, a bioethicist at the NYU Grossman School of Medicine. Jill Grandes, Tennessee Donor Services' executive director said that because of NRP, we're able to save more lives. It's a game changer.

But NRP has sparked an intense ethical debate. The *American Journal of Bioethics* dedicated a recent issue to the controversy over whether the technique blurs the definition of death. "I think the procedure raises very major ethical and legal issues," says Alexander Capron, a bioethicist and lawyer at the University of Southern California. But Sellers and others defend the approach. "It's a very powerful strategy for reducing the organ shortage and helping to improve outcomes," says Brendan Parent.



How to Stay Cool in Extreme heat without air conditioning



## Picnic Plans!!!

We need help planning our upcoming picnic. Our last one took some while to put together. Please try to come and help make our outdoor meeting a fun one again!

**Look, if Cauliflower  
can become pizza  
You, my friend can be  
anything!!!**



## Organ Transplantation Laws Enacted and Being Considered

There are many laws on the books, and some being proposed that affect organ transplantation. The ones below are not exhaustive of the total number. We will continue to list laws of interest as they are discovered and reported. 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 4362:** 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.
- **HR 4343: 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.
- **S1384 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 insurance companies from denying or limiting coverage for organ donation or from charging higher premiums; directs HHS to encourage organ donation.
- **Public Law 116-260, Part 1; December 2020 - Consolidated Appropriations Act of 2021**, calls for CMS to pay all immuno-suppressive drug medication costs for a recipient as needed due to an organ transplant. In the past such payments ended after six months.

### ***Biden-Harris Administration Acts to Advance Kidney Transplant Access***

Today, the U.S. Department of Health and Human Services (HHS), through the Centers for Medicare & Medicaid Services (CMS), is announced the **Increasing Organ Transplant Access (IOTA) Model**. The proposed model, which would be implemented by CMS aims to increase access to kidney transplants for all people living with end-stage renal disease (ESRD), improve the quality of care for people seeking kidney transplants, reduce disparities among individuals undergoing the process to receive a kidney transplant, and increase the efficiency and capability of transplant hospitals selected to participate. This model would build on the collaborative efforts between CMS and the Health Resources and Services Administration (HRSA) to increase organ donation and improve clinical outcomes, system improvement, quality measurement, transparency, and regulatory oversight. "The organ transplant industry, like every other part of society, is not immune to racial inequities," said HHS Secretary Xavier Becerra. "Black Americans disproportionately struggle with life-threatening kidney disease, yet they receive a smaller percentage of kidney transplants. The Biden-Harris Administration is taking concrete steps to remove racial bias when calculating wait times and rooting out profiteering and inequity in the transplant process."



# Let's Stay Connected!



## 2024 Leadership Team

| Role           | Name          | eMail                                                                          |
|----------------|---------------|--------------------------------------------------------------------------------|
| President      | Jim Deyo      | <a href="mailto:jdeyo@att.net">jdeyo@att.net</a>                               |
| Vice-President | Spencer Baker | <a href="mailto:Srbaker98@yahoo.com">Srbaker98@yahoo.com</a>                   |
| Secretary      | TBD           |                                                                                |
| Treasurer      | TBD           |                                                                                |
| Newsletter     | * Bob Bilyeu  | <a href="mailto:Bob_Bilyeu@yahoo.com">Bob_Bilyeu@yahoo.com</a><br>916-675-2721 |



*Editor's Note: If you have topics you'd like us to explore in the monthly newsletter let Bob Bilyeu know.*

**Check Out Our NEW Website!** <https://norcaltransplantsupport.org>

***Let us Know  
What you Think!***

Jan Escamilla, Eileen Chandler, Renee and David Hawkyard,  
Scott Thompson, Jim Deyo, Spencer Baker, Sandy and a few others.

## Important Links



- [American Liver Foundation](#)
- [Donate Life California](#)
- [Sierra Donor Services](#)
- [United Network for Organ Sharing](#)



"I was just glad to get the transplant  
I needed without having to sacrifice  
an animal donor."



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Established 1991

