

# N.C.O.T.S.

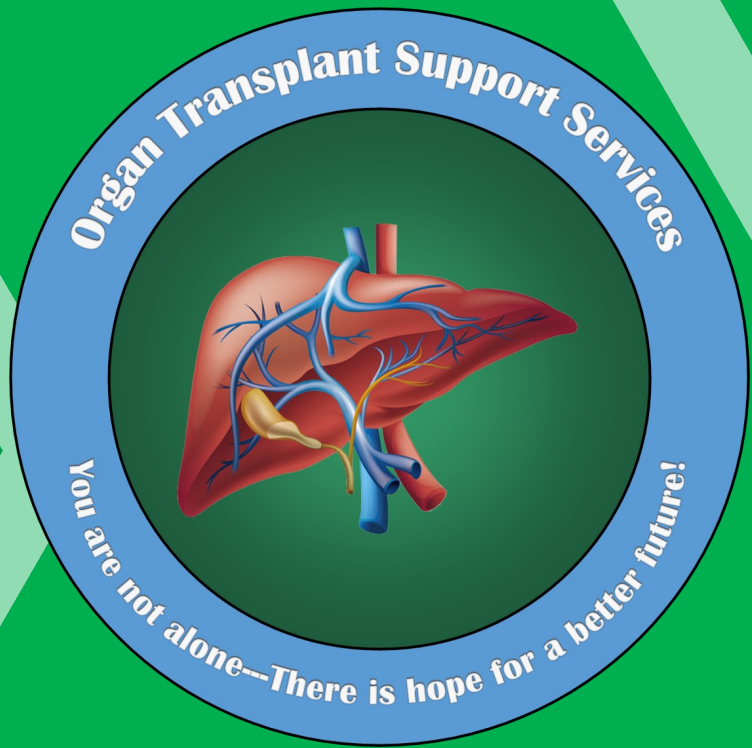
Next Meeting:

Sunday, August 11  
1 pm – 2:30



[Click This Zoom](#)

[Link to Join](#)



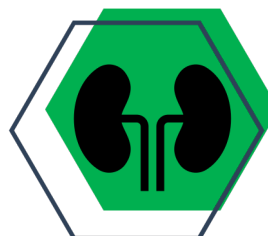
## Monthly Newsletter



AGENDA  
Honoring Organ  
Donation



The Organ  
Procurement &  
Transplantation  
Network



Talking  
About Kidney  
Transplants



Laws Enacted  
&  
Being Considered

"You're braver than you believe, stronger than you seem, smarter than you think."

— A.A. Milne

### Northern California Organ Transplant Support Group

Established 1991





# AGENDA

## Welcome

- ❖ Introductions
- ❖ Discussion-Transplant Articles- West Sac Family
- ❖ Next Picnic & Physical Meeting
- ❖ Ambassador Program
- ❖ Open Discussion
- ❖ Adjournment

## ***Honoring America's Organ, Eye, and Tissue Donors and Recipients***

A life lost is potentially the start of a new life for someone else. The gift of life, that is what organ donation can provide. Recently the United Network for Organ Sharing (UNOS) celebrated 20 years of honoring America's organ, eye, and tissue donors and recipients through the National Donor Memorial, where the names of donors span from one end to the other.

It is a sacred place for organ donor families and transplant recipients from across the country to reflect on the emotional journey of the donation process. Like Kristina Armstead who lost her 8-year-old son Joseph, who donated his liver kidneys, and pancreas. "This wall has been here the entire time we've not had our Joseph. So they've given us a place to come and be with him. So that is how they support us and help us along this road," Armstead said.

Jan Flanders, a three-time tissue recipient herself, says she has pride in what her late husband has given to others. "I had no idea he would be able to donate tissue and corneas so I'm forever indebted," Flanders said. The 10,000-square-foot memorial is located at the UNOS building in Downtown Richmond. If you would like to give the gift of life, you can sign up to be an organ donor by [clicking here](#).

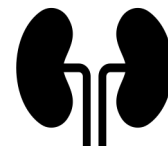
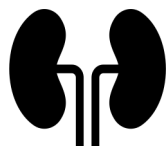
## Remaining 2024 Meeting Dates

|                         |                           |
|-------------------------|---------------------------|
| May 12 <sup>th</sup>    | September 8 <sup>th</sup> |
| June 9 <sup>th</sup>    | October 13 <sup>th</sup>  |
| July 14 <sup>th</sup>   | November 10 <sup>th</sup> |
| August 11 <sup>th</sup> | December 8 <sup>th</sup>  |



## ***A Look at Region 5***

2023 was a record year for organ transplants in the US. It was the first year we exceeded 46,000 separate organ transplants. Records were also set for kidney, liver and heart transplants last year. We are right now on pace to beat those high marks. I thought it would be interesting to see how busy our transplant region (#5) has been this past year. The following table shows that information. One observation we can make is that roughly 20% of all organ transplants in this country were performed in region 5 last year.



# **THE ORGAN PROCUREMENT & TRANSPLANTATION NETWORK**

### **Region 5 Overview:**

**States include:**

- Arizona
- California
- Nevada
- New Mexico
- Utah



### **Region 5 Profile Donors versus Organs Donated in 2023**

| Programs   | Donors | Organs |
|------------|--------|--------|
| All Donors | 3,444  | 9,021  |
| Kidney     | 3,225  | 5,450  |
| Liver      | 1,770  | 1,770  |
| Heart      | 690    | 690    |
| Pancreas   | 126    | 126    |
| Lung       | 505    | 979    |
| Intestine  | 6      | 6      |

# Nobody is G

going to Know if You Don't Talk About it.!!!

*In 2023, for the first time there were over 27,000 kidney transplants*



**Caring for a mother and grandmother with autoimmune diseases, Shamekka** had to grow up young. Now she manages multiple autoimmune conditions of her own, including lupus, which can lead to kidney failure. A self-described “professional patient,” she also keeps up a busy life as a cybersecurity expert, a health advocate, a motivational speaker and a mother of three. Slowing down is not her speed.

In November 2022, Shamekka was listed for a kidney transplant. Because of her complex health profile, she knew she would be a difficult match. She and her husband began exploring living donor kidney paired donation. Then, unexpectedly, came the news. A match was available—on the opposite side of the country. In February 2023, Shamekka received a kidney flown from Connecticut to California.

As someone experienced with navigating the complexities of both chronic illness and the healthcare system, Shamekka is a patient advocate who is a “voice for the voiceless,” she says. She encourages every patient to become their own advocate and to speak openly about their experiences. “I want people to know that if they want change to happen, they have to be a part of it,” she says. “You are trying to raise awareness. **Nobody is going to know if you don't talk about it.**”

More than 14,500 Black patients, disadvantaged by calculations for estimating kidney function, were credited with adjustments to their time on the transplant waitlist.

**2,000**

of these patients received transplants in 2023



## 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](mailto:bob_bilyeu@yahoo.com)

**It's a good idea to communicate  
with your elected representative  
about pro transplantation legislation**

- **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.

# 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](#)

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