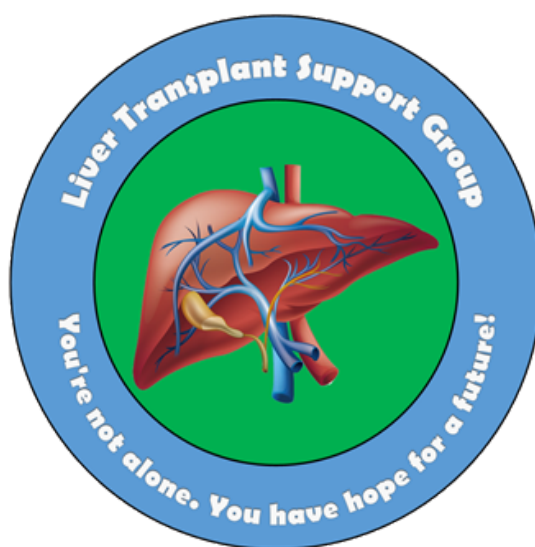


Northern California Organ Transplant Support

www.norcaltransplantsupport.org



Monthly Newsletter May 2023 Volume XV

UNOS Facing Pressure to Change

In March of 2023 the Health Resources and Services Administration (HRSA) called on Congress to help make changes in organ retrieval and distribution in this country. This was no surprise move by the Biden Administration. The call for change follows years of scrutiny, uncovering many examples of available organs being wasted and too many distribution failures resulting in unnecessary deaths. These and other long-standing issues have resulted in various calls for much needed change soon. Currently there is no timeline for change, as many issues are quite complex and thorny. United Network for Organ Sharing (UNOS) officials, for their part have listened attentively and made efforts at reform. However, in past speeches they point to their successes, that the system is working better every year. In 2021, for instance the US performed 41,354 organ transplants, the highest number for any one year since we started keeping records in 1987. There were also ever-higher numbers of kidney, liver and heart transplants in 2021 and 2022. Critics applaud those UNOS efforts and accomplishments but are steadfast in pointing out UNOS has not been serious enough about effecting serious consequential change. Many viable organs made available for transplant are being discarded because the distribution

system is inadequate. Some organs extracted for transplant are viable but aren't being transplanted. Critics argue more people are dying that could be saved if the system operated more efficiently. Look for this debate to continue. But make no mistake, the world of organ transplantation is changing in America. Expect to see changes soon.



Reviving Hope

In the depth of loss a beacon shines, A chance to heal with love's designs,
In selfless acts, a gift profound, And bonds of life are truly found.

A heart that beats in harmony, Once belonged to another, you see,
A life reborn, a chance to soar, Transcending pain forevermore.

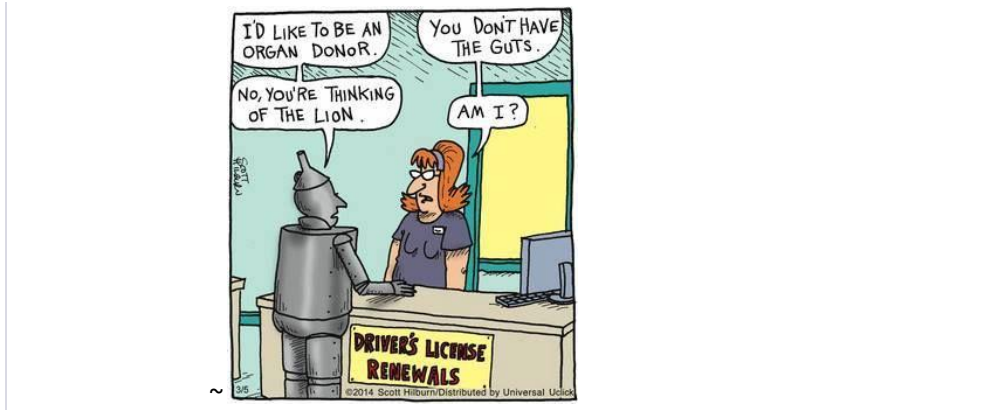
A miracle beholds, through surgeon's hands, As life's melody unfolds,
Transplanting hopes, renewing breath, Uniting souls in the face of death.

A symphony of grace, in each beat, A testament to life's embrace,
A legacy of courage and love, Echoing through the realms above.

Oh, transplantation's sacred art, Where compassion binds every part,
With gratitude, we gather near, To honor those who conquer fear.

For in the giving we find our worth, Reviving hope upon this Earth,
Transplanting life, a miracle's sign, A testament to love's design.

~~~BRB, et al~~~



## California AB 2504

We should be aware of California Assembly Bill 2504 (AB2504, introduced by Ash Kalra, San Jose). It is called the "Living Organ Donor Reimbursement Act." There are many financial reasons why people are reluctant to volunteer to be living donors. Insurance companies and organ transplant hospitals have done lots to help ease the financial strains live organ donation imposes on living donors, but many significant expenses still have to be dealt with. These costs are sizable stumbling blocks to volunteering to be a live organ donor. That's where AB 2504 comes in. The bill authorizes living organ donors to apply to the department of Health Care Services for reimbursement of qualified donation expenses that were not, or will not, otherwise be reimbursed, including travel and lodging expenses, lost wages, childcare costs, copayments and deductibles for prescription and over-the-counter medications needed as a result of the donation. The bill would limit the total reimbursement costs awarded to each living organ donor to \$10,000 per organ donation. Despite the fact organ transplants are increasing every year during at least the past decade and recognizing 2022 saw UNOS organ transplants exceed the one million organ mark, there is little disagreement that too many people are dying in this country because they are not getting that organ transplant they so desperately need. This bill is the first such law being considered in this country and since living organ donation is one area where we could see improving numbers fairly quickly perhaps our group can discuss this at our next meeting and in the future to see if we would like to show our support. The Bill was introduced in 2022 by Assemblyman Ash Kalra of San Jose. It appears to be tabled in Committee, awaiting a hearing.

## Next Meeting: Sunday, May 21 2023

1PM – 3:30PM

To Join Zoom Meeting, Just click on the blue highlighted line below and enter if you dare.

**<https://us02web.zoom.us/j/6737744254>**

**We hope you will be able to make this meeting. We have been receiving calls from various sources asking about our group. We anticipate seeing three new people at our meeting this month. Two of them are pre-transplant patients and one is a member of another support group. Your very presence at the meeting shows them they are not alone, adrift in a vast sea taking them who knows where. We can demonstrate to them the depth and breadth of our organ transplant knowledge and experience. This is a big deal. We can provide help, encouragement and understanding, particularly to those facing transplant. We can give them a better sense of the process and more importantly, see how our transplant improved our lives. As a group, we can make a difference in their lives and provide great comfort. Sometimes just seeing people actively participating in discussions is enough to give encouragement and hope. See you there!!!**

Finally a website presence that tells our tale. If you haven't done so, just type in:

[www.norcaltransplantsupport.org](http://www.norcaltransplantsupport.org)

You will see what your website team has created. Please take the time to go over what was designed by our team of volunteers, Jan Escamilla, Eileen Chandler, Renee and David Hawkyard, Scott Thompson, Jim Deyo, Spencer Baker, Sandy and a few others. They have been working together to come up with an updated and improved presentation of our group. Long time members are no doubt familiar with our beleaguered web footprint that left everyone wondering exactly what we were doing, where we met and when and how to get hold of us. Though we

If you're wondering why we've been so busy...

***Check out our new Website!!!:***

*Let us Know What you Think!*

If you haven't done so, just type in: [www.norcaltransplantsupport.org](http://www.norcaltransplantsupport.org). You will see what your website team has created. It goes a long way toward telling our tale. Please take the time to go over what was designed by our team of volunteers, Jan Escamilla, Eileen Chandler, Renee and David Hawkyard, Scott Thompson, Jim Deyo, Spencer Baker, Sandy and a few others.

### **Agenda**

- Welcome
- Introductions
- Discussion of NY Times Article
- AB2504 \* UNOS Under Pressure
- Social Media & our Presence
  - Open discussion
  - Member Story
  - Adjournment

### **Meeting Dates:**

| 2023          |              |
|---------------|--------------|
| Meeting Dates |              |
| January 8     | July 9       |
| February 12   | August 13    |
| March 12      | September 10 |
| April 16      | October 8    |
| May 21        | November 12  |
| June 11       | December 10  |

*Our Leadership Team*

President – Jim Deyo.....Jdeyo@att.net  
Vice President – Spencer Baker.....srbaker98@yahoo.com  
Secretary..... (to be determined)  
Treasurer..... (to be determined)  
Newsletter –Bob Bilyeu.....bob\_bilyeu@yahoo.com

**Editor's Note:** If you have ideas regarding subjects you'd like to address or if you found value in this newsletter, please let us know. Contact Bob Bilyeu at [bob\\_bilyeu@yahoo.com](mailto:bob_bilyeu@yahoo.com) or call at (916) 675-2721

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