

Meeting at Tempo Park This Month!!!

See Inside

October 19, 2024 Monthly Newsletter

Stan Transplant Support Services

There is hope for a better



Open Letter & Agenda



Liver Walk Physical Meetings



Picnic in the Park



Organ Transplant Laws

"Don't judge your day by the plants you reap but by the seeds you plant."

~~~Robert Louis Stevenson

### Northern California Organ Transplant Support

Established 1991

#### Unfair and Unjustified Criticisms

— More than 1,100 professionals involved in organ transplantation, along with physicians, patients, and donor families, have signed an open letter denouncing an ongoing campaign of misinformation that is eroding public trust in organ donation and threatening the lives of patients awaiting transplants. The open letter warns that national data from Donate Life America (DLA) already demonstrates **a decline in the number of Americans registering as organ donors.** This trend is already seen in 80 percent of states consistently reporting state donor registry data to DLA over the past three years. "For over five years, our nation's organ procurement organizations (OPOs) – the non-profit, community-based organizations that work with grieving families every day to save lives through transplantation – have been subject to malicious misinformation and defamatory attacks based on hearsay, creating a false narrative that donation and transplant in the U.S. is untrustworthy and broken," the letter reads. "Ignored is the fact that there has been 13 years of consistent growth in organ donation by OPOs, leading to a record 43,000 organs transplanted and lives saved through deceased donation last year."

#### An Open Letter to the American Public:

Dear donation and transplant community, policymakers and media: For over five years, our nation's organ procurement organizations (OPOs) - the non-profit, community-based organizations that work with grieving families every day to save lives through transplantation - have been subject to malicious misinformation and defamatory attacks based on hearsay, creating a false narrative that donation and transplant in the US is untrustworthy and broken. Ignored is the fact that there have been 13 years of consistent growth in organ donation by OPOs, leading to a record 43,000 organs transplanted and lives saved through deceased donation last year.

The life-saving work of donation and transplant is too important to be undermined by unsubstantiated accusations as serious as claiming OPOs are hastening death or attempting to recover organs before donors have died –no legitimate evidence has been produced to support these outrageous claims.

Spreading misinformation based on conspiracy theories and hearsay is disturbing in any setting but is particularly dangerous during a Congressional hearing on organ donation and transplantation. Repeating this misinformation erodes the public trust and, in doing so, can cost lives by decreasing the number of people willing to register as donors. There is evidence this is already happening. National data shows a concerning decline in the number of individuals saying "yes" to donor registration over the past three years, making it more difficult to increase the number of lives saved through organ donation.

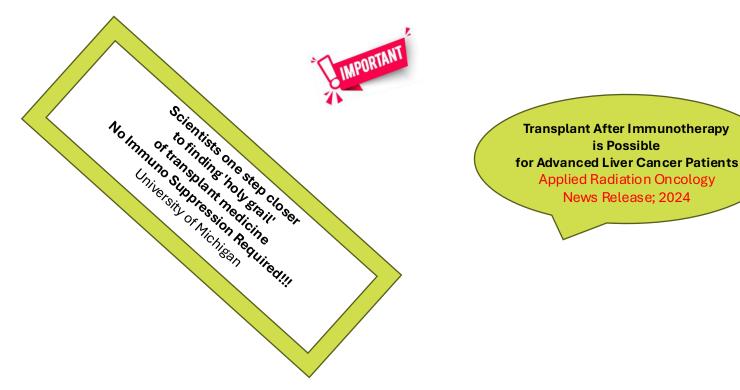
We call upon all those working to improve the donation and transplant system and members of the media who cover it to reject reckless allegations, think critically about what you hear and seek out the actual facts. For years, this misinformation conspiracy campaign, led by people who have never worked in donation, has driven the conversation and policymaking that shapes it. It is time for it to stop. Now is the time for serious and fact-based informed discussions with lawmakers that must include the professional experts who do this work. - September 27, 2024:

[Over 1100 Signatures follow]



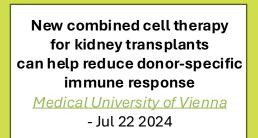
#### AGENDA

#### Advances in Immuno-Tolerance



across. We have been telling our readers that much progress is being made in the organ transplant immuno-therapy world. Right now, people are receiving kidney transplants and not only are they recipients of a new organ and a new life, they're living, thriving and enjoying life without dependence on immune suppressants. Check it out... This world is changing right before our eyes.

SOMETIMES a visual aid is much more effective at getting the message





### It is time to discuss SIERRA DONOR SERVICES

This organ processing organization (OPO) is interested in reconnecting with us. They are also looking for volunteer Ambassadors to help get their message out. We are working on a plan to re-establish meetings at their West Sacramento location. Come help us establish these ties.

#### PICNIC IN TEMPO PARK Saturday, October 19 @ 11:30AM

Special Guests, Stars and Rodeo Clown:

I Can't Wait!!! Come One! Come All! Let's Make This the First of Many.

We Need Everyone to Bring Pot-Luck Items Hamburgers, hotdogs, desserts, drinks

Get Hold of Jim or Spencer for Details!!! (916) 812-4256 or srbaker98@yahoo.com



#### **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: 118<sup>th</sup> 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 4362: 118<sup>th</sup> 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: 118<sup>th</sup> 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 insurance companies from denying or limiting coverage for organ donation or from charging higher premiums; directs HHS to encourage organ donation.

#### *Legislation Proposed in Michigan Living Organ Donors* - a sign of things to come.

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.

Looking ahead, as the bill progresses to the Senate for further deliberation, it is believed making living organ donation more accessible and financially manageable will lead to increased donor rates. This legislation carries the potential to not only save lives but may bring profound, positive impacts to both donors and recipients within local communities. These same advocates urge the public to consider the profound gift of organ donation, highlighting the enduring legacy and lifesaving potential it encompasses.

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 is seen as a critical step in addressing the severe shortage of living organ donors in the state.

This legislation carries the potential to not only save lives but also bring profound, positive impacts to both donors and recipients within local communities. The public is encouraged to consider the profound gift of organ donation, highlighting the enduring legacy and lifesaving potential it encompasses. -from Transplant News; September 30, 2024





| 2024 Leadership Team |               |                                      |
|----------------------|---------------|--------------------------------------|
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| President            | Jim Deyo      | jdeyo@att.net                        |
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| Secretary            | TBD           |                                      |
| Treasurer            | TBD           |                                      |
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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**

### **Remaining Meeting Dates**

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

November 10 December 08

January 12 Febraary 09



Northern California Organ Transplant Support Group

