

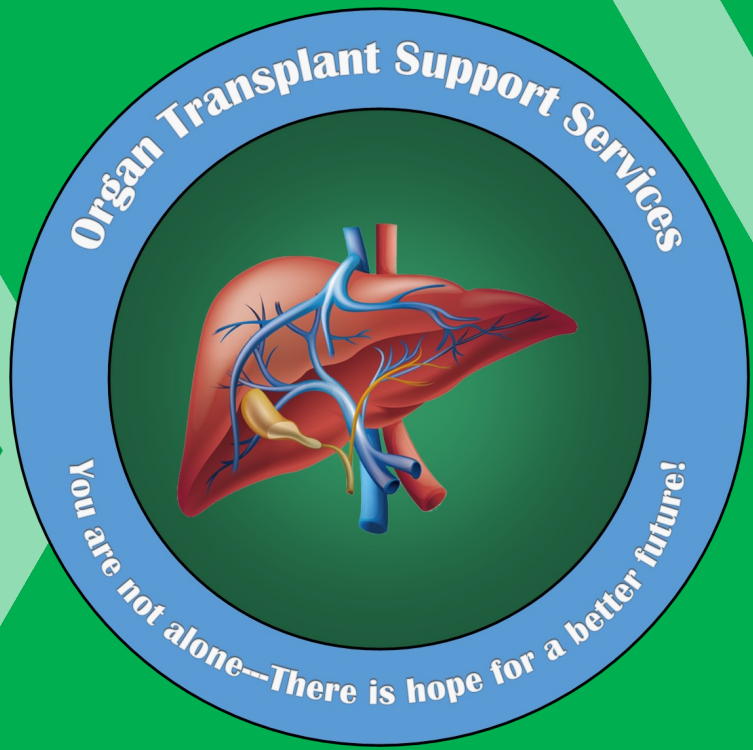
N.C.O.T.S.

Next Meeting:
Sunday, June 9
1 pm - 2:30



[Click This Zoom](#)

[Link to Join](#)



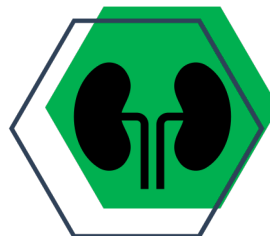
Monthly Newsletter



AGENDA



THE SEARCH FOR
THE HOLY GRAIL



TRIO
SIERRA DONOR
SERVICES



LAWS ENACTED &
BEING CONSIDERED

"The art of life is remembering and using what happens to us."

- Martin Luther King, Jr.



Northern California Organ Transplant Support Group

Established 1991



AGENDA



- ❖ Welcome
- ❖ Introductions
- ❖ Discussing TRIO
- ❖ Sierra Donor Services
- ❖ Our Next Physical Meeting
- ❖ Open Discussion
- ❖ Adjournment



It is time to decide if we are going to maintain our local roots and name or expand our horizons and join Transplant Recipients International Organization (*TRIO*), an organ transplant support group that boasts over 4,000 members nationwide and has been around since 1987. We think by joining them we can increase our local membership and maybe gain access to ideas that will help us broaden our message in Northern California. Jim Deyo and Spencer Baker, our leaders, support this idea.

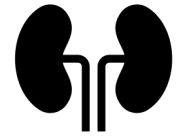
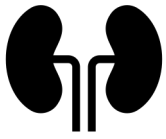
Such an association should make fundraising a little easier and we believe the health of. Our group is dependent on getting out in the community and raising organ donation awareness. That's why we also want to discuss improving our connection to *Sierra Donor Services*. They do a lot of community service. We believe we can restart our association with them and negotiate a way to bring back initially quarterly physical meetings at their location. Your participation in this meeting is appreciated.

Please try to come.

We need your thoughts

Remaining 2024 Meeting Dates	
May 12 th	September 8 th
June 9 th	October 13 th
July 14 th	November 10 th
August 11 th	December 8 th

THE SEARCH FOR THE HOLY GRAIL... (OF ORGAN TRANSPLANTATION)



Organ transplant professionals have been searching for decades for the Holy Grail of organ transplantation, that is, discovering whether transplant recipients can tolerate their new organ and live the rest of their lives without the use of immunosuppressants. Can that be achieved? Can our bodies tolerate any new organ without drugs? It is clear, organ transplantation tolerance is possible, sometimes, according to Dr. Dorry Segev, a transplant surgeon at NYU Langone Health in New York City. Transplantation without vital immunosuppressants seems like wishful thinking to those who have been taking them for years. Nearly all immunosuppressants come with bad side effects. I guess you can ask what drugs don't have side effects? But immunosuppressants come with a host of them, including harming the donated organ itself, increasing the recipient's risk of different kinds of infections, different cancers, and mental acuity and focus sometimes are affected and the list goes on. "The idea that you can actually be off anti-rejection drugs for the rest of that life — there's a lot of benefit in that," said Dr. Sanjeev Akkina, medical director of the kidney transplant program at Loyola Medicine in suburban Chicago. Dr. Akkina is a researcher involved with a Phase 3 randomized, multi-center, open-label, controlled trial on this very subject.

The Phase 3 results were presented Monday, June 3, 2024 at the American Transplant Congress in Philadelphia. They found after two years, 16 of 19 patients were able to come off their anti-rejection drugs entirely. The three other patients had to go back on the drugs due to either a rejection episode or worsening kidney function.

The trial is centered around a stem cell therapy derived from the person donating the organ. The findings have not yet been published in a peer-reviewed journal. But "these are excellent results," said Dr. Jeffrey Veale, a urologist at UCLA Health who specializes in [kidney transplantation](#). Not only were a majority of the patients able to stay off the drugs for two years, they also showed a significant benefit in quality of life for the patients, added Veale.

Kidneys are the most commonly transplanted organs in the US with around 25,000 kidney transplants performed annually in recent years, according to the [Organ Procurement and Transplantation Network](#). Around 10% of them, however, are repeat procedures after a transplanted kidney fails. As work in this field continues many are anticipating great results, eventually. But right now most of the success has come with kidneys only. I recommend you look up articles on this subject; start with NBCNews.com. June3, 2024

Voluntary Organ Donation Works!!!



*Here is one way
to help
a friend or stranger...*

If you would like to help someone you know through **living directed donation**, talk to them and contact the transplant program where the person is listed. If you would like to help someone you do not know by being a **living non-directed donor**, contact a transplant hospital of your choice and ask if they have such a donation program. Go to the [OPTN Member Directory](#) for a list of transplant hospitals. And please talk to your loved ones about your desires.



2023

More than

10,000

liver transplants*



***There were 10,660 liver transplants performed in 2023
the most ever for a single year.***

Last year the U.S. organ donation and transplant community continued a record-breaking trend that started eleven years ago. Some 10,660 liver transplants were performed last year, more than ever performed in a single year, and more than 10,000 for the first time ever. Eleven years of all-time high numbers of liver transplants wouldn't be possible without the generosity of organ donors and their families and the hard work of the countless members of the Organ Procurement and Transplantation Network (OPTN). This historic streak also comes in the wake of the OPTN's work to enact policies such as changes to MELD and PELD calculations to ensure that more people have access to lifesaving transplants.

More changes to liver allocation are coming soon. The Offer Filters Tool is being developed for liver allocation in 2024, and the OPTN Liver Committee is continuing to develop a policy based on continuous distribution. Read more about continuous distribution [here](#).



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

**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	jdeyo@att.net
Vice-President	Spencer Baker	Srbaker98@yahoo.com
Secretary	TBD	
Treasurer	TBD	
Newsletter	* Bob Bilyeu	Bob_Bilyeu@yahoo.com 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](#)

