N.C.O.T.S.

Next Meeting: Sunday, April 14th 1 pm – 3:30



Click This Zoom

Link to Join



Monthly Newsletter



APRIL AGENDA



NATIONAL DONATE LIFE MONTH



STORIES & NEWS



LAWS ENACTED & LEGISLATION BEING CONSIDERED

"Out of a mountain of despair, a stone of hope."

- Martin Luther King, Jr.



Northern California Organ Transplant Support Group



I ordered a chicken and an egg from Amazon. I will let you know...

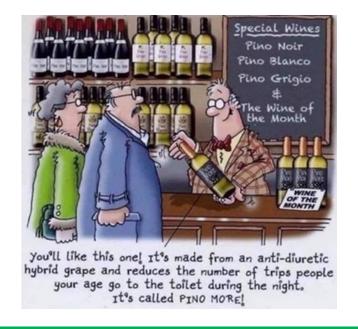
AGENDA

- Welcome
- Introductions
- New Therapies
- Open Discussion
- 2024 Transplant Games
- ❖ Member Story
- ❖ Adjournment



Our message is getting out there! Not about the chicken and the egg. We've been taking calls about our group. We anticipate meeting new people this month. Your very presence at the meeting shows them we care and tells them they are not alone, adrift in a vast sea, taking them who knows where.

Together, we can demonstrate 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, show 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 encouragement and hope. See you there!!!



Remaining 2024 Meeting Dates		
May 12 th	September 8 th	
June 9 th	October 6 th	
July 14 th	November 10 th	
August 11th	December 8 th	



HELP!!! Too many people dying because they can't get an organ transplant.

Each April Donate Life America (DLA) focuses national attention on the need for organ, eye and tissue donation. It's about the importance of registering your decision to be a donor, honoring deceased and living donors, and celebrating the lives they saved. It is the generosity of donors and donor families that makes saving lives through transplantation possible. Currently there are more than 100,000 patients waiting for transplant right now.

Uncounted thousands more should be on that list but aren't for several reasons, including especially supply shortages. We need more volunteer donors.

The demand for organs always exceeds supply in the transplant world. It is a fact more people are being saved from organ failure every year. The United Network for Organ Sharing, UNOS has transplanted more than a million organs since 1988, when records started being kept. Yet too many people are dying before they even get on a list, while unacceptable numbers are dying while waiting. Depending on the source 17 to 23 people are dying every day because they can't get a needed transplant in time. The absolute need for more organ donor volunteers is undeniable and medical data suggests it is going to get worse as time gets deeper into the 21st century. The problem isn't going away. The life a donor may save one day could be a loved one, or through some peculiar, odd twist of fate, their own. Volunteering spurs further volunteering, doesn't it?

People suffering from organ failure are often invisible to those outside their immediate circle. And the view from the outside is always blurry and unclear, like looking though a dirty window. You don't see the worry, the fear, confusion, anger and other feelings a person faces when told they need an organ transplant. You can't see the effect this news has on everyone concerned. From the outside you can't see a father sitting at the kitchen table wondering how he's going to tell his wife and son he needs an organ transplant, or he is going to die. And you don't see how family members and friends are affected. People need to be jolted into seeing how important organ donation is to the millions of us out here wondering how we got into this mess and how we're going to get out. When you suffer from organ failure wondering why that is happening and then having to wait are challenging. Obviously, not getting the transplant is worse.



Organ Transplants Allows Our Stories to continue

"Wyndham Clark, a professional golfer and a teenage heart transplant recipient recently shared an inspiring message of hope and resilience. Clark, who underwent a life-saving heart transplant at the age of 13, has not let his medical journey hinder his dreams and ambitions. At a recent event, he addressed a group of teenagers who have also undergone organ transplants, highlighting the importance of staying positive and pursuing their passions.

Clark's story serves as a reminder of the incredible resilience shown by individuals who have undergone organ transplants. Despite facing numerous challenges, Clark has not only survived but thrived in his pursuit of a professional golfing career. He shared his personal motto of "every day is a good day" with the young audience, encouraging them to adopt a similar outlook in their journey towards recovery.

The teenager who received Clark's message expressed her gratitude and shared how meeting him had inspired her to stay positive and persevere through her own medical journey. Wyndham Clark's story represents a testament to the human spirit and the power of determination, motivating others facing similar circumstances to embrace hope and chase their dreams despite the difficulties they may encounter."*

* Taken in its entirety from <u>www.transplantnews.com</u>



TRANSPLANT NEWS!

First Patient With a 'Pigney' Transplant is Discharged from Hospital!



Click the photo below to view a short video





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.

Let's Stay Connected!

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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
- > UNOS

The only parking spot
I found at the hospital
was in the C-Section.
So, I left my car
through the sunroof.



