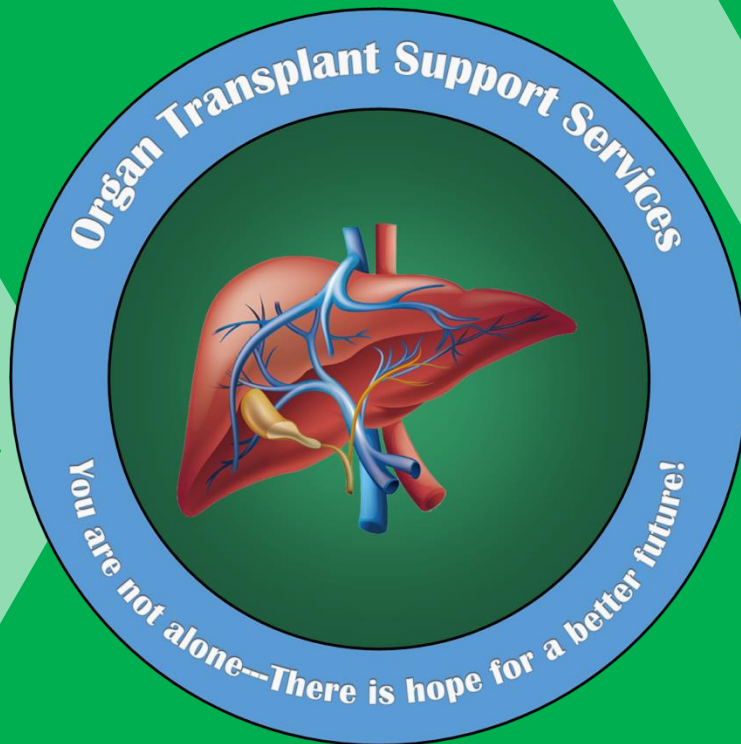


**N.C.O.T.S.**  
[norcaltransplantsupport.org](http://norcaltransplantsupport.org)

**Next Meeting:  
Sunday,  
November 10  
1 pm – 3:00**



[Click This  
Zoom Link to Join](#)



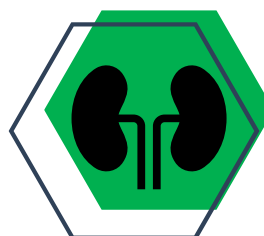
# November 10, 2024 **Monthly Newsletter**



Kidney Donor Profile  
Agenda



Liver Walk  
Physical Meetings



Picnic in the Park



Organ Transplant  
Laws

*“DON'T COUNT THE DAYS, MAKE THE DAYS COUNT.”*

~~~Muhammed Ali

***Northern California Organ Transplant Support***

Established 1991

# KIDNEY DONOR PROFILE INDEX CHANGES

## *Race and hepatitis C status*

no longer used to assess deceased donor kidney function;  
policy change anticipated to increase distribution equity

On Oct. 31, 2024, the Organ Procurement and Transplantation Network (OPTN) implemented a new policy revising the Kidney Donor Profile Index (KDPI), a calculation that summarizes the quality of deceased donor kidneys according to several criteria. The revised KDPI now excludes two variables used in the previous calculation:

1. Whether the potential donor is African American/Black
2. Whether the potential donor has tested positive for the hepatitis C virus (HCV)

In addition to removing race and HCV, score components for the remaining deceased donor characteristics which make up the KDPI have been adjusted to compensate for the removal of those two variables. You can read the policy notice and Board briefing paper for additional details.

The OPTN board of directors believe these policy changes will give authorities an improved and more accurate estimate of the probability of graft failure from all donors. Though race has been and is still used as a variable in many ways and circumstances, it is a poor proxy for human genetic variation and innovations in treatment have made post-transplant outcomes for HCV positive deceased donor kidney transplants similar to that of HCV negative donor kidneys. Therefore, this new calculation is anticipated to increase equity and transparency in the nation's procurement and transplantation system. The Organ Procurement and Transplantation Network believes removing these criteria will have a positive impact on decreasing the wasting of unused donor kidneys.

*Published on: Thursday, October 31, 2024*

## *A HISTORIC STEP!!!*

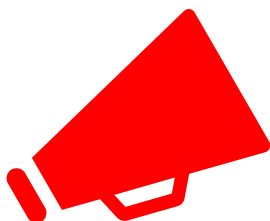
### **HRSA Makes First Ever Multi-Vendor Awards to Modernize the Nation's Organ Transplant System and end the Current Contract Monopoly**

*As part of the Administration's efforts, for the first time in the program's nearly 40-year history, HRSA has awarded separate contracts to reform the organ procurement and transplant network. Multiple vendors will support improving quality and patient safety, modernizing IT, bolstering communications with patients, and more.*

*This is one of the more important policy actions taken by the organ transplant world in several years. The system we became quite familiar with in our experience with organ failure is busier today than ever before. Go to the internet and check this out. This story is much bigger than I have space to devote to it. Read: [www.hhs.gov](http://www.hhs.gov) > about > news > 2024/09/19*

## AGENDA

- ❖ Welcome and Introductions
- ❖ Liver Life Walk - Nov 2
- ❖ Physical Mtgs and Picnic
- ❖ Liver Life Walk
- ❖ Comstock Magazine Interview
- ❖ Discussion: Transplant Articles
- ❖ Ambassador Program Spkr
- ❖ For December Meeting
- ❖ Adjournment



# CHANGES AT UNOS



Securing the U.S. Organ Procurement & Network Act, 09, 2023  
reduces inefficiencies and promotes equity.  
public law 118-14 (09/22/2023) @ [www.congress.gov/house-bill](http://www.congress.gov/house-bill)

**Patient survival Rate Post Organ Transplant**  
Varies at all points of inquiry for various reasons. Plus, we are all different and so are all donors. However, patient survival rates at one, three, five and 10 years hover at 91%, 86%, 81% and 78% respectively.  
<https://pmc.ncbi.nlm.nih.gov/articles>

Transplantation

The world of UNOS, the United Network for Organ Sharing, is fascinating. I'm not sure any layman will ever completely understand it. The subject has so many moving parts in a world that's continually moving independently around. It's so complex, so diffuse. There are patients, of course, and loved ones, and medical professionals of all types within the medical care community, and because America is America, there are advocates and interested parties and the government making demands on everyone. And the stakes are so high for everyone, aren't they? Consider just one piece: the world of the surgeon and other medical professionals dealing with organ transplants: they are all top notch, they are learning new techniques, new dangers, new opportunities, continually updating their skill levels, finding or forging new approaches and new tools so they can do more transplants each year. Their lives are constantly changing. Because of them more people are getting a second chance at life, and they are living longer and healthier. Change is the operative word for these folks. I thought I might highlight some of the big change areas I'm aware of and show you where to get information about those and related topics.

## CHECK IT OUT...

The Transplant world is changing right before our eyes.

### •Organ Transplantation Affinity Group (OTAG)

- A federal collaborative group
- that aims to improve access to
  - organ transplantation.

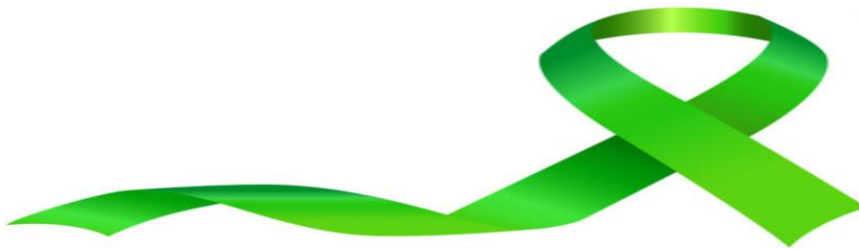
See [optn.transplant.hrsa.gov](http://optn.transplant.hrsa.gov) > [hrsa-and-cms](http://hrsa-and-cms)

**New Medical Advances**  
allow more organs from donors who die after their heart stops beating to be used in transplants. These organs were previously typically unused. **All these equal more donors**

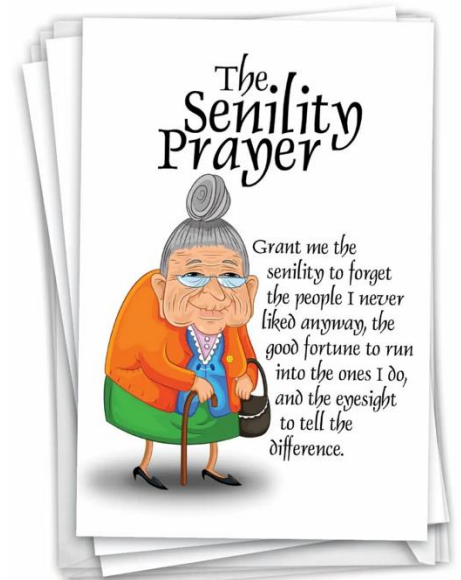
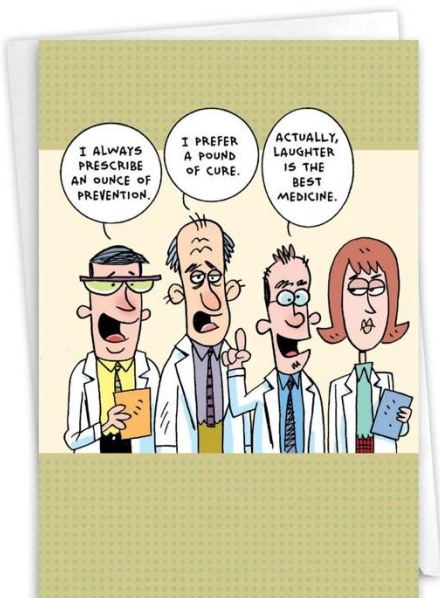
## **PIG KIDNEY TRANSPLANTS ARE ONGOING AND NEEDED!!!**

The medical community has been experimenting with xenotransplantation since before the first human to human kidney transplant took place in 1954. It is a difficult, expensive, time-consuming endeavor. But efforts like this are essential and must continue. Since we officially began transplanting organs in 1987 there has always been a larger demand than a supply. We all know there is no end in sight to this negative demand-supply dynamic. In fact, those who should know say demand is expected to rise much higher in the decades just ahead of us. We must endeavor to improve form and function everywhere in this ever-changing and apparently ever-needing world.

We reported in this newsletter on the success reached by a team of surgeons at Massachusetts General Hospital (MGH) this past year when they transplanted a genetically modified porcine kidney transplant into Mr. Richard Slayman, who survived two months before he passed from an unrelated illness. That gave hope to thousands of people. Researchers were involved in another experiment involving genetically "humanized" (as opposed to genetically modified) pigs, whose kidneys kept cynomolgus macaques (also known as long-tailed Macaques-monkeys) alive for up to two years. We also reported on an effort at UCLA Medical Center who has been working on performing specific kidney transplants on particular patients & recipients, where recipients won't need to use immuno-suppressants anymore. Researchers believe these efforts will also see successes with certain other organs.



**Sierra Donor Services**  
*Looking for motivated  
Ambassadors to help  
them get the word out!  
Give them a call!*





## 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 state faces a critical shortage. According to Gift of Life Michigan, around 2,000 residents are awaiting a [kidney](#) 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 to 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



# 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 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



- [American Liver Foundation](#)
- [Donate Life California](#)
- [Sierra Donor Services](#)
- [United Network for Organ Sharing](#)

## Remaining 2024 Mtg Dates

November 10  
December 08



Northern California Organ Transplant Support Group

Established 1991

