NORTHERN CALIFORNIA ORGAN TRANSPLANT SUPPORT



UNOS INTRODUCES CONTINUOUS DISTRIBUTION

The United Network for Organ Sharing, UNOS has announced how organ distribution is changing. Despite seeing remarkable progress not only in terms of the number of organ transplants performed each year and the increasing number of lives being saved annually, there has always been a desire to make improvements where possible. Organ distribution is one such area where change is happening right now. UNOS is following an approach called 'Continuous Distribution'. This new policy change is radically different than what is currently being used.. I will give you a brief look at this change here but will refer you to specifics below. First of all, Continuous Distribution ensures no single factor determines placement. The new framework moves organ allocation from considering and placing patients in categories such as blood type, antibody sensitization, geographic location, etc, to leveraging big data analytics and considering multiple factors all at once using an overall scoring system that operates on a sliding scale. The timetable for this distribution policy change follows::

Lung: implemented on March 9, 2023

Heart: expected to take effect in 2023

VCA: expected to take effect in 2023. - VCA means vascularized Composite Allografts

Kidney-Pancreas: expected to take effect in 2024

Liver: policy development in process

For detailed information, see unos.org, but many articles exist explaining continuous distribution in detail; see https: optn.transplant.hrsa.gov, https: optn.transplant.hrsa.gov, YouTube UNOS News, March 28, 2023, https://www.optumhealtheducation.com, YouTube, Video: How is continuous distribution different, April 5, 2023

June 11 Meeting Notes

Our June 11 meeting began on **ZOOM** at 1:15PM. In attendance were Jim Deyo, Spencer Baker, Eileen Chandler, Kelly Carlisle, Pam Stratford, Scott Thompson, a new member whose last name is Tyler (Pre-transplant), Nancy B., Nima, President of the San Francisco Bay Area Trio Support Group, and Bob Bilyeu. After initial general discussion members introduced themselves and gave a brief description of their personal journey into the world of organ transplantation. There was some discussion about an outdoor picnic or pot-luck occasion in one of the many parks in Sacramento. A date was not set, but a preference of possibly September was mentioned. Jim said he would bring the subject up in July's meeting. Renee' Hawkyard had previously suggested Stanford Ranch in Antelope, but others thought Rusch Park and Carmichael Park were good possibilities. There was discussion about costs but the estimate of \$160 is within the group's budget for such a meeting. Bob pointed out there was not much more than that available. Eileen pointed out not very many people attended our last in-person meeting, so possibly the whole idea should be re-examined. There was general discussion about pre and post-transplant problems people experienced at different times and Jim opined it was vital people be careful when using the internet as a source of information. Much of the information we get from the internet comes from people who only think they know what they are talking about; it's important to always consult your doctor or your medical team when you have questions about anything having to do with organ transplants. Jim also advocated people use the Scientific Registry of Transplant Recipients (SRTR). SRTR is an excellent source of analytics on all aspects of organ transplantation. Bob brought up the subject of the need to get a good, reliable caregiver. Jim Deyo brought up the subject of Dexter Barry, the heart recipient who recently died in the Jacksonville city jail because he couldn't get his immunosuppressants. Beyond the tragic story of his death, we did learn from his doctor (according to Jim and supported by Scott Thompson) that heart issues can be brought on by Prograf (Tacrolimus) and shortness of breath may also be a derivative of Prograf usage. It was mentioned that Sierra Donor Services still has an ambassador program and if anyone is interested in getting involved with them they are located at 3940 Industrial Blvd, West Sacramento. You can call them toll free at 877-401-2546 or contact them at sds.info@dcids.org. The meeting adjourned at 2:56PM.



I got not one comment last month about the illustration below I think it's funny. It stays until someone says, "Come on, Bob!

We get it. You think you're funny. Great find!!!"

I know, I know, my ego has no limits on the depths to which it can sink.



A very good friend of mine works at Ikea in North Sacramento. His birthday is July $30^{\rm th}$. I thought I would buy him a cake for the occasion. He can get his own candles.

C'mon!!! This is funny!!!

Five Ways AI Affects Organ Transplantation Now and in the Future:

- Preventing the need for a transplant. Researchers have been analyzing data that is designed to
 aid doctors in detecting organ failure early. All is also being used to help recipients find ways to help
 in their own recovery and hopefully experience fewer post operative problems, thereby improving
 lives.
- 2. Improving organ donor/recipient matching. Matching organs is complex and troublesome at best. But AI can and does improve and speed up the matching process. A Mayo Clinic study* describes how an AI scoring system could be used to analyze transplanted kidneys with an eye toward improving the health of the new kidney. That study was found in Wiley Information Library, Clinical Transplantation, Vol 37, Issue 1, November 2022.
- 3. **Increasing the number of usable organs.** Targeted improvements in transplant technology with perfusion machines for kidney and increasingly with livers is a great example of this idea.
- 4. **Preventing Organ Rejection.** The risk of organ rejection is a big challenge in transplant medicine. We are turning to AI to identify patients most at risk for organ rejection. Deep learning studies on electrocardiogram data has developed non-invasive detection of cardiac allografts without biopsy. AI Scoring systems have also come into play here for kidneys (see 2 above).
- 5. Improving Care After Transplant. Because immuno-suppressants can cause potentially harmful side effects, it is critical to determine the minimum dose necessary for patients to remain healthy. All could one day be used to help determine how a patient's body reacts to immunosuppression and guide when medications should be adjusted. There is hope All will eventually make posttransplant care easier for patients, eliminating the need for routine biopsies and blood draws.

This Month's Meeting: Sunday, July 9 2023 1PM – 3:30PM

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

https://us02web.zoom.us/j/86734291346

Meeting ID: 867 3429 1346

We hope this Sunday you can make our meeting. We've been averaging ten people in attendance in 2023. We would like to see more, of course, but we recognize everyone leads busy lives. Nevertheless, we are a support group, and as such our success in helping people with pre and post-transplant issues depends on us being there when we can in order to provide the benefits of our knowledge. The fact is the United Network for Organ Sharing (UNOS) is either the tip of the spear or being pushed along by the tip of a spear to make several changes in policy and function in America's organ transplant system. Change is already underway concerning how lungs are being distributed to those in need of a transplant since March of this year. Significant changes regarding the transplanting of livers is scheduled to begin soon. We won't be able to go into all UNOS changes, but this meeting can start peeling back some of the layers UNOS is affecting. Last month you learned here that we have been receiving calls from various sources asking about our group. We anticipate seeing new people coming to our meetings as time passes. If you haven't been to a meeting recently, now is a good time to check us out. Your very presence at the meeting shows pre and post-transplant folks they are not alone, adrift in a vast sea taking them who knows where. Who knows more about post-transplant issues and how they can be dealt with than us? 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 to people who are having real problems. As a group, we can make a difference in people's lives and provide great comfort. Sometimes just seeing people actively participating in discussions is enough to give encouragement and hope. Hope to see you there!!!

Don't Forget to check out our Website!!!:

Let us Know What you Think!

If you haven't done so, just type in: 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

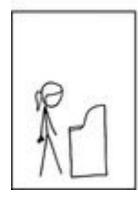
Welcome
Introductions
New UNOS Policies
Social Media Footprint
Next Physical Meeting
Open discussion
Member Story
Adjournment



I think we should call IPhone chargers Apple Juice











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

	Our Leadership Te	<u>'eam</u>	
	President – Jim [Deyo	
Jdeyo@att.net	Secretary	ersrbaker98@yahoo.com (to be determined)	
determined)	Treasurer Newslette	(to be ter –Bob	
Bilyeu	bob_bilyeu@yahoo.com		
-		I like to address or if you found value in this lyeu@yahoo.com or call at (916) 675-272	1

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<u>UNOS</u>

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