

Northern California Organ TRANSPLANT Support

Monthly Newsletter

April 2023 - Volume XII



Sunday, April 16. -- 1:00 pm - 3:00 pm

A Zoom presentation

To Join the **Zoom** Meeting just click on the highlighted link below and you may enter,

if you dare.

<https://us02web.zoom.us/j/87902171367>

Remember: April is National Donate life Month

**Check Out Our New Website
Let Us Know What You Think**

Finally a website presence that tells our tale. If you haven't done so, just type in: www.norcaltransplantsupport.org. You will see what your website team has created. 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. They have been working together to come up with an updated and improved presentation of our group. Long time members are no doubt familiar with our beleaguered web footprint that left everyone wondering exactly what we were doing, where we met and when and how to get hold of us. Though we have spent quite a bit of time on it, we recognize there may be some things left out and others that need a little wordsmithing, but I think you will find this a pretty good step in the direction we want to go. Be prepared to go over the site on Sunday the 9th of April at our next meeting.

Changes Ahead for UNOS Organ Transplant Policies?

We have spoken to widespread criticisms the United Network for Organ Sharing (UNOS) has been exposed to over the years. This pressure is continuing to build and is coming from more than a few vocal outsiders. It truly seems like salvo after salvo of criticisms regarding many aspects of organ transplantation are coming to a head right now. These investigations and likely recommendations for change were suggested in 2022, the year UNOS performed its 1,000,000th organ transplant since records have been kept beginning in 1987. It's also the second straight year UNOS exceeded performing over 9,000 liver transplants in one year and continued its string of 9 consecutive years of exceeding the previous year's mark. Plus, it should be noted in 2022 UNOS performed over 42,000 organ transplants, another milestone. Even though UNOS can point to numerous achievements over the years, including increasing the number of deceased and live donors every year, many are saying UNOS numbers are not high enough. There are too many people not getting the organ transplants they need, and too many people are dying needlessly. Other points of contention have to do with the outdated data system used by UNOS. UNOS claims the data system is proprietary and therefore not subject to outside scrutiny. Being able to limit oversight of the data UNOS gathers makes it easy to suggest information may not be updated enough to meet changing needs. Moreover, the argument goes, the UNOS system must operate within an extremely complex arena where all organ transplant distribution issues have to be resolved within 11 geographical regions impacting fair and equitable organ distribution. Another area of concern has to do with inefficient organ procurement operations, or OPOs throughout the country. There are many issues UNOS has to deal with in the coming months having to do with equity among all people and it would behoove people who have some interest in the system to check out what is being said. For its part UNOS has made it clear they are receptive to these criticisms and is ready and willing to work with anyone to improve what they are doing. But the writing may already be on the wall; the American system may need to be reshaped to include competitive bidders and stockholders. The Health Resources and Services Administration, HRSA will issue bids for new contracts in the fall but wouldn't say how many. The Centers for Medicare and Medicaid Services, CMS, has also stepped up inquiries into UNOS/OPO practices and the Biden administration has pledged to look into UNOS practices in 2023. Be prepared to see some major changes, major overhauls to what is being done today. If you're interested in the changes that are being talked about, there are many articles you can check out on the NET.



I imagine this little girl feels somewhat intimidated and uncertain when she ponders those waves coming in and the challenges of that body of water. I remember feeling similarly about life in general while I stood in line for a liver transplant for 18 years, from 1996 until 2014. Everything during that time seemed intimidating. I started coming to our monthly support meetings around 2006. During many of those meetings I was confused, troubled and often lost. As you know liver failure can do that to you. But I usually left those meetings with a little hope in my pocket. I got to see organ recipients who had suffered just like me. Almost everyone in those meetings, like those of you today, know what I'm talking about. People were smiling, thoughtful, engaging, enjoying life, participating. Pre-need and recipients alike knew what organ failure was like, what it could do to you. I got to look at recipients as Veterans of surviving through dangerous, uncertain times. Each of them, each of you showed me it was possible to recapture who I was. Organ recipients know it is possible to regain that spark of life that grows dim with chronic organ failure. The transplant isn't really the end, though, is it? Recipients have to worry about taking immuno-suppressants the rest of our lives, possible serious side effects, possible organ failure due to rejection and other issues, but they generally pale in comparison to the problems we faced with organ failure. There will be more people waiting for an organ transplant every year. There will be a lot of people standing out there on the shoreline wondering if they will ever put a toe in the water again, if they will ever again attempt to swim.

Meeting Notes For April

Our next meeting begins at **1:00PM**. We will convene remotely on **ZOOM**. Given last month's meeting was our first physical meeting in three years, and since there were difficulties getting some people hooked up electronically, we will discuss last month's meeting to some degree. We will likely cover the following:

- Welcome new members
- Introductions
- Review updated website
- Discuss social media
- Open Discussion
- Member story

Notes from Last March:

Minutes Not Available
March 12, 2023

The meeting began - at 1:15PM
Agenda

1:15 PM	Welcome
1:25 PM	Introductions.
1:35 PM	Discussion of our Net Presence
1:45 PM	Discussion of Social Media
2:00 PM	Open Discussion
2:30 PM	Member Story
2:55 PM	Announcements Future Meetings
3 00 PM	Adjournment

UC DAVIS Med Center Reopening Liver Transplant Program!!!

With the arrival of Dr. Sophoclis Alexopoulos as Chief of the Division of Transplant Surgery at the UC Davis Medical Center, plans are underway to reopen their liver transplant program in the next few months. Dr. Alexopoulos is an experienced transplant surgeon with expertise in adult and pediatric transplantation as well as complex liver cancer surgery. It has been nearly 15 years since that program ceased operating in May of 2009. Hopefully many Sacramento area liver patients can shorten their commute hours to UCSFMC and other Bay Area transplant centers.

Meeting Dates:

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

Our Leadership Team

Facilitator – Jim Deyo.....Jdeyo@att.net
 Facilitator – Spencer Baker.....srbaker98@yahoo.com
 Secretary..... (to be determined)
 Treasurer..... (to be determined)
 Newsletter - Bob Bilyeu..... .bob_bilyeu@yahoo.com

Editor’s Note: If you have ideas regarding subjects you’d like to address or if you found value in this newsletter, please let us know. Contact Eileen Chandler at eileenchandler@yahoo.com or Bob Bilyeu bob_bilyeu@yahoo.com

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