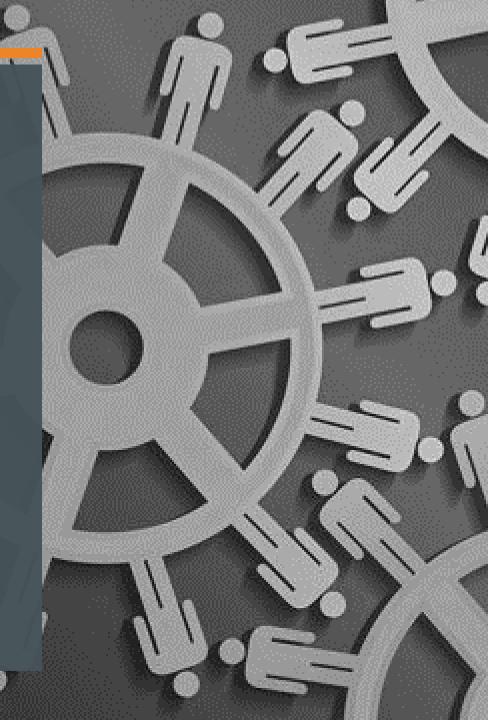
MAXIMIZING THE TOOLS OF THE TRADE: RESOURCES FOR LIVING DONOR PROFESSIONALS

#### ELLEN SHUKHMAN RN, BSN, AMB-BC, CCTC

Supervisor Of Clinical Operations Living Kidney Donation & Paired Donation Programs Cedars-Sinai Comprehensive Transplant Center Ellen.Shukhman@cshs.Org



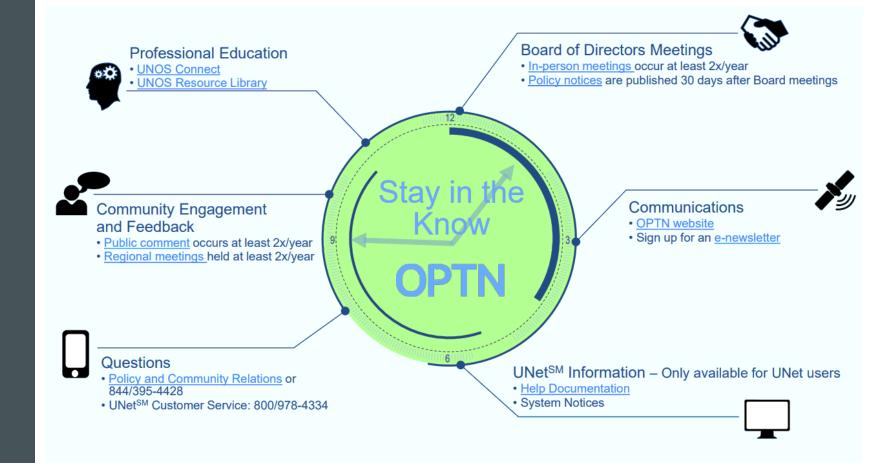


### **CONTENT:**

- PROFESSIONAL ORGANIZATIONS
- KIDNEY PAIRED DONATION RESOURCES
- CALCULATION TOOLS
- GENERAL RESOURCES
- MISCELLANEOU RESOURCES
- FINANCIAL RESOURCES

# UNOS

UNITED NETWORK FOR ORGAN SHARING (UNOS)



Opportunities to Get Involved:

- Board of Directors
- Committee membership
- Public Comment Forum

Living Donor Committee

Transplant Coordinator Committee

### UNOS Board of Directors

Transplant Administrators Committee

**Ethics** Committee



### **Educational Resources:**

- Professional Education:
  - UNOS Connect
- Toolkits
- Professional events:
  - Regional Meetings
  - Transplant Management Forum
- Patient Education:
  - UNOS Transplant Living
- OPTN:
  - Patient & Professional Resources



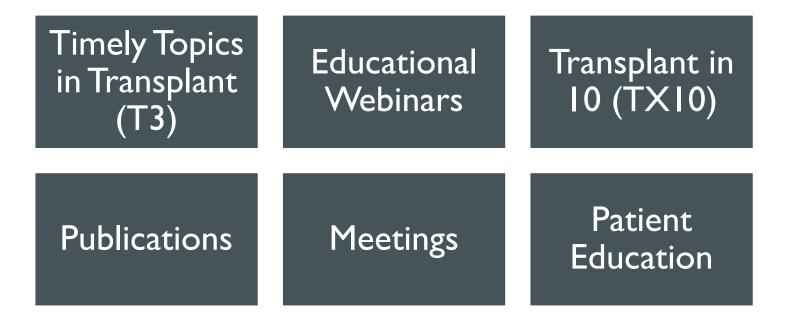
Organ Procurement and Transplantation Network



# AST

### AMERICAN SOCIETY OF TRANSPLANTATION







#### Advanced Practice Providers

- Community of Transplant Scientists
- Infectious Disease
- Kidney Pancreas
- Live Donor
- Liver and Intestinal

• Pediatric

Join a COP!

- Psychosocial and Ethics
- Recovery and Preservation
- Thoracic and Critical Care
- Trainee and Young Faculty
- Transplant Administration and Quality Management
- Transplant Diagnostics
- Transplant Pharmacy
- Transplant Regenerative Medicine
- Women's Health

#### • Finances Workgroup

- LD International Donors Workgroup
- Education/Communication Workgroup
- Living Liver Donor Toolkit
  Workgroup
- Telemedicine Workgroup
- Mental Health Workgroup
- Kidney Paired Donation
  Workgroup



### **Professional Education:**

Introductory Course for the Transplant Professionals

### **Professional Development:**

- Guide to onboarding New Professionals
- Core Competency Guidelines
- One-on-one individual career development plan
- Emerging Leaders program



NORTH AMERICAN TRANSPLANT COORDINATORS ORGANIZATION

#### **Certification Review Courses & Certifications:**

- Virtual CCTC Review Course
- CCTD Certified Clinical Transplant Dietitian (CCTD)

#### **NATCO Academy Webinars:**

- Regulatory Impact on Transplantation
- Transplant Immunology and Histocompatibility Parts I & II
- Living Organ Donation and Informed Consent
- Nutritional Evaluation of the Living Kidney Donors
- Promoting Health span and Longevity for Living Organ Donor
- Social Media and Organ Transplantation: Successfully Navigating the Next Frontier

#### **Conferences:**

NATCO Annual Meeting



### **Opportunities to Get Involved:**

Listserv:

NATCO Connect

Committees:

- Living Donor Committee
- Ethics Committee
- Public Policy Committee
- Research Committee

Workgroups:

- Education Workgroup
- Quality Work

### **Publication:**

- Journal: NATCO Progress in Transplantation
- Newsletter: InTouch
- Textbook: A Clinician's Guide to Donation and Transplantation
- Manual: Kidney Independent Living Donor Advocacy Training Documentation Manual





### NATIONAL KIDNEY FOUNDATION

#### **NKF Patient Education / Resources:**

- RECIPIENTS: The Big Ask / The Big Give
- DONORS:
  - Overview of Living Donation
  - NKR Blog
  - NKR Peer Support <u>NKFpeers@kidney.org</u>

#### **Living donation**



When you donate an organ to someone else,

you are providing a life-sustaining gift.





Making the decision

Consider the following before making the decision to become a living donor.



The Evaluation

The evaluation process ensures that you are healthy enough to donate a kidney.



The more you learn about your surgery, the

better choices you can make about your

The Surgery

health.



Things to consider

Find out what questions to ask yourself as you go through your decision-making process.



After donation

All about living well with one kidney.

### **NKF Professional Resources:**

Clinical Tools:

GFR Calculator

Continuing Education Opportunities

Living Donor Advocate Listserv:

Council of Professional Living Donor Advocates (CPLDA)

Publication:

- American Journal of Kidney Disease: Evaluation of Kidney Donor: Core Curriculum (2018) (Sawinski & Locke, 2018)
- Advances in Chronic Kidney Disease
- Journal of Nephrology Social Work





AMERICAN FOUNDATION FOR DONATION & TRANSPLANTATION (AFDT)

#### **Advancing Professional Education:**

- Basic and Advanced Histocompatibility Training Course
- Living Donation Conference
- Transplant Quality Institute

### Living Organ Donor Network:

- Donation-related insurance for living kidney donors over a period of 2 years
- Donor tracking over a period of 2 years

**Accidental Death & Dismemberment Insurance** 

#### **Public Education on Living Donation**

#### **Professional Education**

Free OnDemand Webinars:

- Bioethics
- Disincentives and Barriers to Living Donation
- Informed Consent
- Living Donor Evaluation
- Living Donor Resources
- Living Organ Donation
- Medical Alibi
- Paired Kidney Donation

Independent Living Donor Advocacy Services

**Community Awareness** 



THE LIVING BANK



### INTERNATIONAL TRANSPLANT NURSES SOCIETY

### **Professional Development:**

- ITNS Education Center
- CCTC/CCTN Review Course

### **Opportunities to Get Involved:**

- Chapters
- Committees / Taskforces
- Annual Meeting:
  - Submit and Abstract
  - Abstract Reviewer Task Force
- ITNS Speaker's Bureau
- Young Professional Committee
- ITNS Central



AMERICAN SOCIETY OF TRANSPLANT SURGEONS

### **Patient Education:**

- Living Kidney Donation: What You Need to Know
- Living Kidney Donation: What you Need to Know (Spanish)
- Living Liver Donation: What are the Risks and Benefits
- Living Liver Donation: What are the Risks and Benefits (Spanish)





We cover topics like cultural misconceptions, treatment options, steps to

and immigrant issues. This website was designed to inform and empower prospective donors, patients, and family and friends about living kidney

become a living donor, risks and benefits of donation, financial issues,

interactive games, and descriptions of resources and policies. Greater awareness about the risks and benefits of living kidney donation will help Hispanic/Latino patients and families to make more informed treatment

donation through the use of testimonials, interviews, telenovelas,

decisions.

Donating is voluntary. Donors can stop the donation process at any time. »

Living donors can be anyone who is healthy enough to donate. »

The recipient's insurance pays for the cost of the living donor's surgery and post-operative care. »

#### **EXPLORE** Transplant

() y 💿 🗖 Q

Home Why transplant matters For kidney patients For family & friends For providers Transplant news About us

### **Explore Transplant education**



Explore Transplant is a series of education programs that have helped tens of thousands of kidney patients nationwide make an informed choice about their treatment options. The materials are available in English and Spanish.

The centerpiece of the program is a series of 4 videos that guides patients through their transplant decision-making process. There is a lot to know! That's why Explore Transplant was created for kidney patients who may be thinking about a kidney transplant. Patients have just started thinking about their options, or may be close to choosing one. There are many things patients think about such as, "Should I stay on dialysis?", "Is transplant for me?", and "How will this affect my loved ones?"

### **EXPLORE** Transplant

## KIDNEY PAIRED DONATION RESOURCES



## NATIONAL KIDNEY REGISTRY







ALLIANCE FOR PAIRED KIDNEY DONATION (APKD)



### **KPD Standard Acquisition Charge**

### **Donor Protection Program:**

- Travel Reimbursement
- Insurance coverage:
  - Health
  - Life
  - Complication
  - Disability
- Wage Reimbursement
- A Kidney Pledge:
  - Protection for nondirected living kidney donors
- Remote Donation

### MedSleuth (MatchGrid):

- Internal Exchanges
- Partnership between Alliance For Paired Kidney Donation and MedSleuth for Regional and National HUBs through the MatchGrid program



# NATIONAL KIDNEY REGISTRY

### Donor Shield Program:

- Lost wage reimbursement
- Limited Travel & lodging reimbursement.
- Life insurance
- Disability insurance
- Coverage for uncovered donor complication costs.
- Legal support.
- Advance Donation Voucher Programs:
  - Standard Voucher
  - Family Voucher
- Remote donation
- Kidney Prioritization

### **OPTN Kidney Paired Donation Pilot Program** (KPDPP)Patient Education

- Video Series:
  - What is KPD
  - Is KPD right for me? Prospective Recipient
  - Is KPD right for me? Donor
  - KPD success stories
- Brochure (English & Spanish)

### **Professional Education / Resources:**

- Kidney Paired Donation Toolkits:
  - Join us
  - KPD policy and resources
    - KPD Quarterly Newsletter
    - Histocompatibility testing
    - Financial resources
    - KPD e-manual
- Listserv: KidneyPairedDonation@unos.org



UNOS KIDNEY PAIRED DONATION PROGRAM

### TOOLS OF OUR TRADE



### CALCULATORS AND RISK ASSESSMENT TOOLS

#### **GFR / CKD-Epi Calculators:**

- GFR with Cystatin C (with and without BSA) <u>https://www.kidney.org/professionals/KDOQI/gfr\_calculator</u>
- GFR with Serum Creatinine and Cystatin C: <u>http://mdrd.com/</u>
- CKD-Epi Adults (mg/dL):

https://www.niddk.nih.gov/healthinformation/professionals/clinical-tools-patientmanagement/kidney-disease/laboratoryevaluation/glomerular-filtration-rate-calculators/ckd-epiadults-conventional-units

CKD-Epi Adults (umol/L):

https://www.niddk.nih.gov/health-

information/professionals/clinical-tools-patient-

management/kidney-disease/laboratory-

evaluation/glomerular-filtration-rate-calculators/ckd-epiadults-si-units

GFR Estimation: <u>http://www.medcalc.com/gfr.html</u>

#### 24-hour Urine Calculated Creatinine Clearance:

- Cornell University: <u>http://www-</u> users.med.cornell.edu/~spon/picu/calc/crclcalc. <u>htm</u>
- MedCalc: <u>http://www.medcalc.com/crcl.html</u>

#### **Decision Models:**

- ESRD Risk Tool for Kidney Donor Candidates: <u>http://transplantmodels.com/esrdrisk/</u>
- Post-donation Risk of ESRD in Living Kidney Donors: <u>http://transplantmodels.com/donesrd/</u>
- Living Kidney Donor Risk Index (LKDPI) <u>http://transplantmodels.com/lkdpi/</u>

### Risk of Recurrence of Kidney Stones (2018):

https://qxmd.com/calculate/calculator\_438/roksrecurrence-of-kidney-stone-2018

### **GENERAL RESOURCES**

Psychosocial Questionnaires/Tools:

- CAGE <u>https://www.psychcongress.com/saundras-corner/scales-screeners/alcoholism/cage-questionnaire-cage</u>
- LDAT -<u>https://www.mountsinai.org/files/MSHealth/Assets/HS/Care/Transplant/Living-Donor/LDATTool.pdf</u>

Ethical Considerations:

TransplantEthics.com

Peer Support:

- Living Donors Online <u>http://livingdonorsonline.org/</u>
- American Transplant Foundation <u>https://www.americantransplantfoundation.org/programs/mentorship-program-2/</u>
- Donate Life Ambassadors living donor volunteers can share their experience through community outreach events (contact your local Donate Life organization)
  - https://donatelifecalifornia.org/ways-to-help/volunteer/
  - https://www.donornetworkwest.org/volunteers/
  - https://www.donorsl.org/get-involved/volunteer/volunteer-groups/
  - <u>https://www.life-source.org/ambassadors/</u>
  - https://lifelineofohio.org/get-involved/volunteer/

### MISCILLANEOUS RESOURCES

### Staffing concerns:

• Transplant Recruiters https://transplantcoordinatorsofamerica.com/

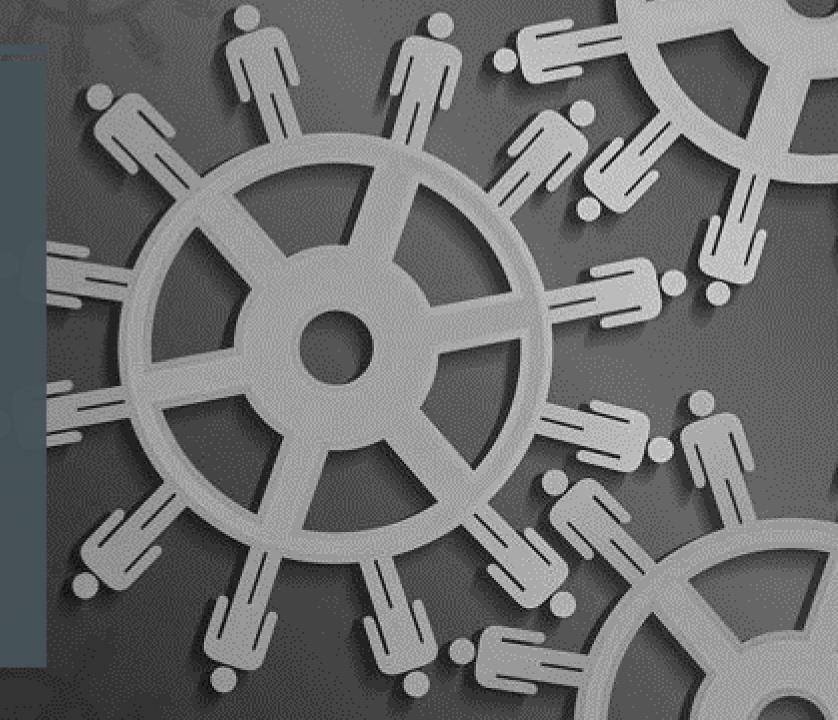
### Transplant Transportation:

- Sterling Global https://sterling.quick.aero/
- NORA https://www.noratrans.com/
- Transplant Transportation Services
  <u>https://www.transplanttransportationservices.com/</u>

### FINANCIAL RESOURCES

- National Living Donor Assistance Center
  - https://www.livingdonorassistance.org/
- American Living organ Donor Fund
  - <u>https://www.helplivingdonorssavelives.org/</u>
- American Transplant Foundation -
  - <u>https://www.americantransplantfoundation.org/programs/pap/</u>
- Heal With Love Foundation
  - <u>http://www.healwithlovefoundation.org/index.html</u>
- American Kidney Fund (Safety Net grants)
  - <u>https://www.kidneyfund.org/financial-assistance/information-for-patients/#safety\_net\_grants</u>
- State-specific programs:
  - Georgia Transplant Foundation
    - <u>https://gatransplant.org/our-programs/financial-assistance-programs/living-donor-assistance/</u>
  - Iowa Anatomical Gift Public Awareness and Transplantation Fund
    - https://idph.iowa.gov/anatomical-gift
- Fundraising:
  - National Foundation for Transplants (fundraising) <u>https://transplants.org/</u>
  - Help Hope Live (fundraising) <u>https://helphopelive.org/</u>
  - Children's Organ Transplant Association (fundraising) <u>https://cota.org/</u>

# QUESTIONS?



### REFERENCES

- Alliance for Paired Kidney Donation. (2020, August 13). Kidney Donation & Transplant : Matching Living Kidney Donors. Alliance for Paired Kidney Donation |. https://paireddonation.org/
- American Foundation for Donation and Transplantation (AFDT). (2021). Organ Donation and Transplantation Support Services | Richmond, VA - American Foundation for Donation and Transplantation. Afdt.org. <u>https://www.afdt.org/</u>
- American Kidney Fund. (2021). Kidney patient financial assistance. Kidneyfund.org. https://www.kidneyfund.org/financialassistance/information-for-patients/#safety\_net\_grants
- American Living Organ Donor Fund. (2020, October 28). American Living Organ Donor Fund. American Living Organ Donor Fund. https://www.helplivingdonorssavelives.org/
- American Society of Transplantation (AST). (2021). American Society of Transplantation. American Society of Transplantation. https://www.myast.org/
- American Society of Transplant Surgeons. (2021). ASTS American Society of Transplant Surgeons. Asts.org. https://asts.org/
- American Transplant Foundation. (2019, November 19). I+I=LIFE Mentorship Program. American Transplant Foundation. https://www.americantransplantfoundation.org/programs/mentorship-program-2/
- American Transplant Foundation. (2021, March 29). Patient Assistance Program. American Transplant Foundation. https://www.americantransplantfoundation.org/programs/pap/
- Bramstedt, K. (2012). Transplant Ethics. Transplantethics.com. http://transplantethics.com/
- Children's Organ Transplant Association. (2016). Peter Hernandez. Children's Organ Transplant Association. https://cota.org/
- Georgia Transplant Foundation. (2020). Living Donor Assistance | Georgia Transplant Foundation. Georgia Transplant Foundation. https://gatransplant.org/our-programs/financial-assistance-programs/living-donor-assistance/
- Heal with Love Foundation. (2021). Heal With Love Foundation. http://www.healwithlovefoundation.org/index.html
- Help Hope Live. (2020, July 10). Medical Fundraising Site for Bills and Expenses Help Hope Live. Help Hope Live. https://helphopelive.org/

- Hu, C.Y. (2021). MedCalc: Glomerular Filtration Rate Estimation. Medcalc.com. http://www.medcalc.com/gfr.html
- Iowa Department of Public Health. (2021). Anatomical Gift Public Awareness and Transplantation Fund. Iowa.gov. https://idph.iowa.gov/anatomical-gift
- Johns Hopkins School of Medicine. (2016). Epidemiology Research Group in Organ Transplantation. Transplantmodels.com. http://transplantmodels.com/
- Living Donors Online (LDO). (2021). Living Donors Online. Living Donors Online. http://livingdonorsonline.org/
- MDRD Calculator. (2013). MDRD.COM. Mdrd.com. http://mdrd.com/
- Mount Sinai. (2018). Live Donor Assessment Tool (LDAT). In https://www.mountsinai.org/files/MSHealth/Assets/HS/Care/Transplant/Living-Donor/LDATTool.pdf. https://www.mountsinai.org/files/MSHealth/Assets/HS/Care/Transplant/Living-Donor/LDATTool.pdf
- NATCO. (2021). The Organization for Donation and Transplant Professionals | NATCO. NATCO. https://www.natcol.org/
- National Foundation for Transplants. (2021, April 14). Home National Foundation for Transplants. National Foundation for Transplants. https://transplants.org/
- National Institute of Diabetes and Digestive and Kidney Diseases. (2021, April 16). CKD-EPI Calculator for Adults (SI Units) | NIDDK. National Institute of Diabetes and Digestive and Kidney Diseases. https://www.niddk.nih.gov/health-information/professionals/clinicaltools-patient-management/kidney-disease/laboratory-evaluation/glomerular-filtration-rate-calculators/ckd-epi-adults-si-units
- National Kidney Foundation. (2021). Welcome The National Kidney Foundation. National Kidney Foundation; https://www.kidney.org/
- National Kidney Foundation of Illinois | Informate'. (2015). Informate HRSA Treatment Options: Dialysis, Transplantation, and Donation. Informate.org. <u>http://informate.org/treatment\_options/</u>
- National Kidney Foundation. (2012). GFRF Calculator. National Kidney Foundation; https://www.kidney.org/professionals/KDOQI/gfr\_calculator
- National Living Donor Assistance Center. (2020). National Living Donor Assistance Center > Home. Livingdonorassistance.org. https://www.livingdonorassistance.org/
- Nationwide Organ Recovery Network. (2020). Nationwide Organ Recovery Network. Nationwide Organ Recovery Network. https://www.noratrans.com/

- Psychiatry & Behavioral Health Learning Network. (2021). CAGE Questionnaire (CAGE). Psychiatry & Behavioral Health Learning Network. https://www.psychcongress.com/saundras-corner/scales-screeners/alcoholism/cage-questionnaire-cage
- QxMD. (2018). ROKS Recurrence Of Kidney Stone (2018) | QxMD. Calculate by QxMD. https://qxmd.com/calculate/calculator\_438/roks-recurrence-of-kidney-stone-2018
- Sterling Global Aviation Logistics. (2020). Sterling Global Aviation Logistics. Quick.aero. https://sterling.quick.aero/
- The Living Bank. (2020). *The Living Bank*. Livingbank.org. https://www.livingbank.org/
- Transplant Recruiters Staffing Agency. (2021, March 12). Transplant Recruiters Staffing Agency. Transplant Recruiters Agency. https://transplantcoordinatorsofamerica.com/
- Transplant Transportation Services. (2019). Transplant Transportation Services Transplant Transportation Services.
  Transplanttransportationservices.com. https://www.transplanttransportationservices.com/
- United Network for Organ Sharing | UNOS | US Organ Transplantation. (2021, April 13). UNOS. https://unos.org/
- Weill Medical College of Cornell University. (2021). Creatinine Clearance. Cornell.edu. http://www-users.med.cornell.edu/~spon/picu/calc/crclcalc.htm