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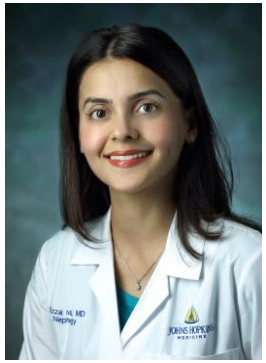
Thanks to our Speakers!



- Fizza Naqvi, MD
  - Assistant Professor at the Department of Medicine (Nephrology), Johns Hopkins
  - Attending physician at Johns Hopkins hospital. Involved with kidney recipient evaluation and co-chair of selection committee.

- Macey Henderson, JD, PhD
  - Assistant Professor of Surgery and Nursing at Johns Hopkins University
  - Research scientist and expert in living donation; member of living donor selection committee.

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The transplant evaluation, waiting list, and more – how to prepare for a kidney transplant

Fizza Naqvi, MD

Macey Henderson, JD, PhD

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Introduction

- Kidney transplant is the treatment of choice for late stage chronic kidney disease (CKD) or end stage renal disease (ESRD).
- For most (not all) patients, transplant can restore a healthy, productive life.
- The effects of CKD/ESRD can persist in patients despite transplant.

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Supply vs. Demand

- Deceased donor kidney transplants steadily increased to more than 12,000 in 2016.
- Live donor kidney transplants approximately 5,600 per year.
- Patients waiting for a deceased donor transplant was more than 100,000 by mid-2016.

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Function of Kidneys

- Make urine and maintain fluid balance
- Remove toxins/waste products
- Maintain chemical balance in the body
- Control blood pressure
- Maintain bone health
- Help make red blood cells

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GFR Cut-off for Transplant

- Kidney function is measured as glomerular filtration rate (GFR).
- You qualify for transplant when GFR or kidney function falls below 20 ml/min/1.73 m^2.
- Ideal to undergo a preemptive transplant—get a transplant before requiring dialysis—referrals can be made once GFR is 30 ml/min.

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Transplant vs. Dialysis

- Regular dialysis provides < 15% waste removal of two normally functioning kidneys.
- Patients on dialysis often feel unwell.
- Patients may be dependent on others for physical, emotional and financial assistance.
- Longer time on dialysis = higher risk of death

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Transplant vs. Dialysis

- A study that looked at 110 studies involving1,961,904 patients found that kidney transplantation was associated with lower risk of mortality, cardiovascular events and better quality of life.

Source:Tonelli M et al,AJT 2011

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Deceased vs. Living Donor

- Deceased donor kidney
  - Standard criteria, high KDPI (>85), PHS increased infectious risk
- Living donor
  - Related or unrelated, paired kidney exchange

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Deceased vs. Living Donor

- Deceased donor transplant half-life = 10 years
- Living donor transplant half-life = 15 years

Note: There is a vast range of kidney transplant survival. These estimates are not certain or fixed.

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Kidney Donor Profile Index (KDPI)

- Estimate of the quality of the kidney
- Percentile ranking from 1-100%
- The lower the number, the longer the survival of the kidney transplant compared to other kidneys.

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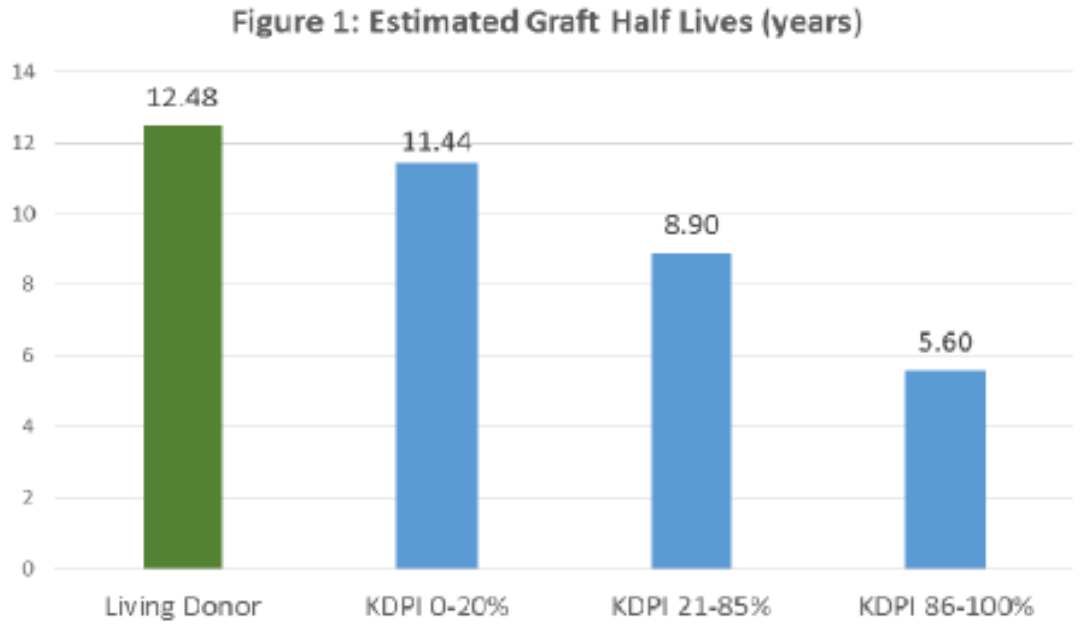
Kidney Donor Profile Index (KDPI)



OPTN-HRSA data

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Survival Benefit

- Expected Post Transplant Survival (EPTS) scores estimate how long a patient will need a functioning kidney compared to others i.e. live longer.
- Low KDPI kidneys (longer estimated function) are allocated to patients with low EPTS scores (better post transplant survival).

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Increased Risk Donors

- ***One in 5 donors is now classified as increased risk.***

- Certain factors including the donor's sexual activity, history of intravenous drug use, history of incarceration in the past year etc. can lead to them being classified as PHS (Public Health Service) increased risk donors.
- Kidney survival and patient survival with these organs is equal or often better than non-increased risk organs.
- All donors undergo testing prior to transplant to check for infections.
- Risk of transmission of infection is very low—approx. 1 in 1000.

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Benefits and Risks

Benefits of transplant

- Improved quality of life, without the need for dialysis
- Decreased mortality and morbidity

Risks of transplant

- Risk involved with surgery
- Lifelong immunosuppression
- Potential for serious infections and cancers

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Choosing a Transplant Center

- Considerations
  - Distance
  - Insurance
  - Experience of transplant team
- Resources
  - Finding a center: https://optn.transplant.hrsa.gov/members/member-directory/
  - Data on centers: https://www.srtr.org/

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Choosing a Transplant Center

- SRTR has data to help compare the outcomes from different transplant centers.
- It provides information on the number of transplants performed at the center in the past year, rate of transplant and 1 year outcome.

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Transplant Evaluation

- Blood tests
- Cardiac tests
- Other imaging
- Screening tests for malignancy
- Immunizations
- Dental clearance

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Additional Tests *(if applicable)*

- CT scan of chest, abdomen and pelvis
- Pulmonary function tests
- 6-minute walking test
- Doppler ultrasound of carotid vessels (neck)
- Brain imaging (CT or MRI)
- Cardiac catheterization

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Evaluation Considerations

- Severe, uncontrollable conditions with limited life expectancy *(fewer than 5 years)*
- Active or incurable cancer
- Ongoing or recurrent infections not treated well
- Serious heart disease or peripheral vascular disease
- Severe liver disease *(may be a candidate for combined liver and kidney transplant)*

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Evaluation Considerations

- Serious and recurrent noncompliance *(missing dialysis or other appointments)*
- Uncontrolled psychiatric conditions or active substance use
- Limited, irreversible rehabilitation potential

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Evaluation Considerations

- HIV
- Age
- Cognitive or neurodevelopmental delay

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Selection Process

- Review of medical, surgical and psychosocial information
- Patient may be cleared to be listed on the national decreased donor waiting list or further testing may be needed.

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Wait Listing

- ***Active:*** You are accruing time on the wait list and eligible for offers.

- ***Inactive:*** You are accruing time but not eligible for offers.

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How Organ Matching Works

Transplant center enters medical data for the patient into UNOS computer system

⇩

Computer network links all organ procurements organizations (OPOs) with all the transplant centers

⇩

When an organ is available, OPO enters medical data for the donor into the computer system and a rank order list ‘match run’ of candidates is generated

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Recipient Factors

- Blood type
- Waiting time
- Donor/recipient tissue match
- Distance from donor hospital
- Survival benefit
- Prior living donor
- Pediatric status

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Wait Time for Deceased Donor Kidney Is Region Specific

Blood Type	Median Wait
O	5 years
A	3 years
B	5 years
AB	2 year

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Wait Listing at Multiple Centers

- There is one national waiting list but within it, organs are distributed locally and regionally.
- By listing in multiple transplant centers under different organ procurement organizations, you may increase your chances of getting an organ.

Note: Insurance may not cover costs at multiple centers. You will need to be able to cover costs of staying close to a center post-transplant.

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On-Call Process

- Target patient
- Back-up to the target patient

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Living Donation - Basics

- ~1 in 4 people were willing to donate if they knew someone in need (NKF survey)
- Two main types of living donation
  - Directed donation (related or unrelated)
  - Non-directed donation (altruistic)

You don't need to have the same blood type or be a "match" to donate.
If you have a healthy, willing donor, the transplant team can likely find a way to make your transplant happen

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Living Donation Benefits

- Minimal wait time
- Work better and last longer than deceased donor kidneys
  - Worse case scenario: If donor develops kidney failure, he/she is given priority on the wait list
- Shortens wait time for others
- Surgery is scheduled, giving donor and recipient time to plan
- Preemptive transplant can allow the patient to avoid dialysis
- Cost of donor's medical care is covered by recipient's insurance or Medicare*

**Time off from work, travel expenses, lodging and other incidentals are not covered—but please contact the National Living Donation Assistance Center for this type of support* www.nldac.org

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Paired Donation

- Exchange organs with another donor/recipient pair to make a better match
- This can be between two pairs or more.
- Goal: find the best possible kidney for each recipient.

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Recovery Post-Living Donation

- 2 days in the hospital
- 4-6 weeks for full recovery
  - *Return to work in as little as 2 weeks*
- Will require temporary pain medicines
- No dietary restrictions after donation
  - *Recommend a healthy, balanced diet*
- No physical activity restrictions after recovery

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Finding a Living Donor

Identify social networks:

- People
  - Family
  - Friends
  - Neighbors
  - Coworkers
  - Religious groups
  - Recreational groups
  - Volunteer/ charity groups
  - Hobbies (golf, bowling, etc.)
- Media
  - Local newspaper
  - Community flyers
  - Church bulletin
  - E-mail groups
  - Blogs
  - Facebook
  - Personal website
  - Twitter

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Finding a Living Donor

Using social networks:

- Plan ahead
- Ask for help
- Approach group/community leaders ahead of time
- Brainstorm the most appropriate ways to approach people (in person, over the phone, via email, etc.)
- Plan what to say in advance
- Post bulletins or flyers that allow people to contact you
- Give people contact information for the transplant center

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Finding a Living Donor

Having conversations with potential donors:

- Things you SHOULD do:
  - Introduce yourself
  - Be honest and use facts
  - Be respectful
  - Use your educational materials
- Things you CANNOT do:
  - Pressure someone
  - Use force
  - Bribe someone
  - Pay someone

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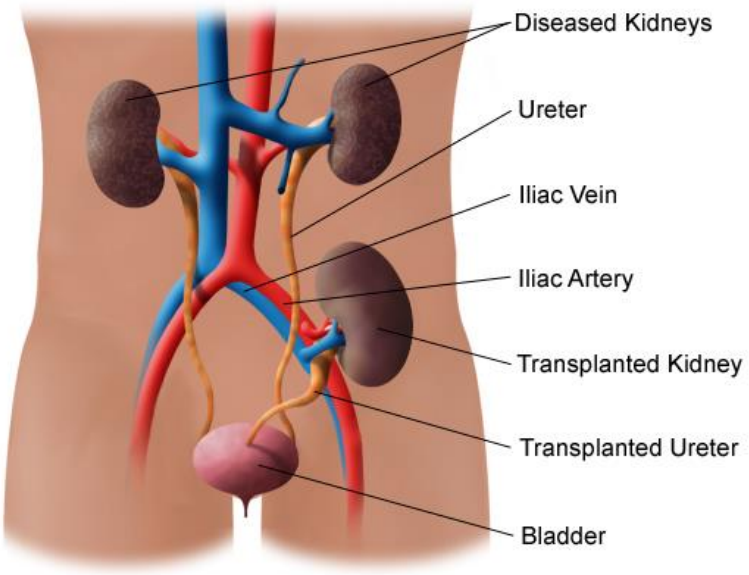
Transplant Surgery

Example of a Kidney Transplant



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Medications

- Immunosuppressive or anti-rejection medications
- Antibiotics and anti-virals
- Medication to prevent heartburn/gastritis
- Blood pressure medication
- Diabetes medication
- Cholesterol medication
- Pain medication *(temporary)*

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Hospital Stay

- Some patients may have delayed graft function and may require dialysis for some time.

- Average length of stay
  - Living donor surgery: 3 to 4 days
  - Deceased donor surgery: 4 to 7 days

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Post-Transplant Care

- Post-transplant coordinator
- Follow-up appointments
- Frequent lab and medication dosage monitoring
- Resources: http://www.kidneyfund.org/training/webinars/adjusting-to-life-after-kidney-transplant.html

Note: Patients of reproductive age need to discuss plans for birth control and pregnancy during this time. Immunosuppressive medications can lead to birth defects.

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Important Points to Remember

Be engaged with your health care team!

- Stay in touch with your transplant coordinator.
- Keep your contact information up to date.
- Update your transplant center on any changes to your health or medical history.
- Make sure your blood sample is received by the immunogenetics lab every 30 or 90 days. You can do this by checking with your coordinator.

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Reliable Health Information

- **American Kidney Fund**
  www.kidneyfund.org/transplant

- **United Network for Organ Sharing**
  www.unos.org

- **American Society of Transplantation**
  www.myast.org

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Next Month's Webinar

Daniel Cukor, PhD

Associate Professor

SUNY Downstate Medical Center

Depression & Kidney Disease

Wednesday, May 23, 2018 | 1-2 p.m. (EST)

- Recognizing the signs of depression
- The connection between kidney disease and depression
- Ways to manage and treat depression

Visit KidneyFund.org/webinars to register

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Q&A

1. **If cancers or other illnesses are disqualifiers for transplant, how is HIV not one of these?**
   There has been significant development in the treatment of HIV and patients with HIV can now live close to normal lives provided they take medications and the virus is under control. As a result, this is no longer felt to be a disqualifier.

2. **How often is KDPI within the 0-20% range? Are KDPIs higher than 20% more common?**
   I can tell you that at our center, most of the kidneys have KDPI between 35-85 followed by 0-20 and 21-34.

3. **Can taking immunosuppressants increase the risk of having a child with birth defects for both men and women?**
   Yes, though way more so for females. One of the first line medications can cause birth defects more often than the other medications and so we have to be careful with all females of child bearing age. For males, this medication is not a cause for concern but rather a second line agent (not used as commonly) that can be a problem

4. **If you find a friend or family member who is a match, do you still need to go on the waiting list?**
   Yes, we place all patients on the wait list since unexpected last-minute issues can still happen with the potential donors. For patients who have a living donor, this wait list acts as a backup.