



PKD FOUNDATION

Polycystic Kidney Disease

Transplantation: Getting to Know Your Transplant Center

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Speaker



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Objectives

- Explain tests that make up the transplant evaluation.
- List requirements for living donors.
- Describe factors to consider when choosing a transplant center.
- Review MB Tips **(bolded)** – **information not necessarily written anywhere.**

How am I qualified to speak about this topic?

- Registered Nurse
- Transplant Nurse Coordinator for Kidney, Pancreas and Liver
- Transplant Administrator for Mayo Clinic and UC Davis
- Living Kidney Donor



Donor & Recipient 2010

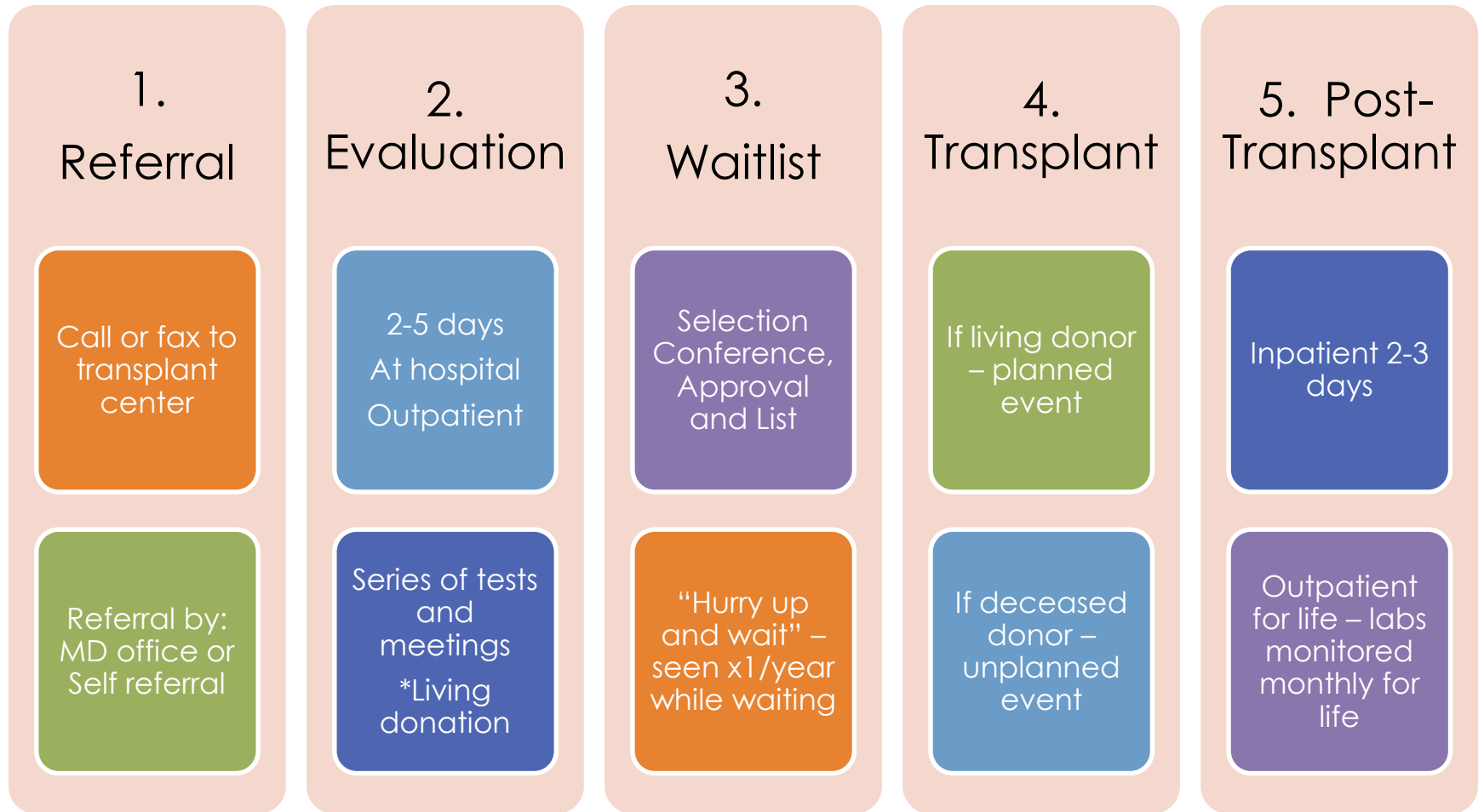


Disclaimer

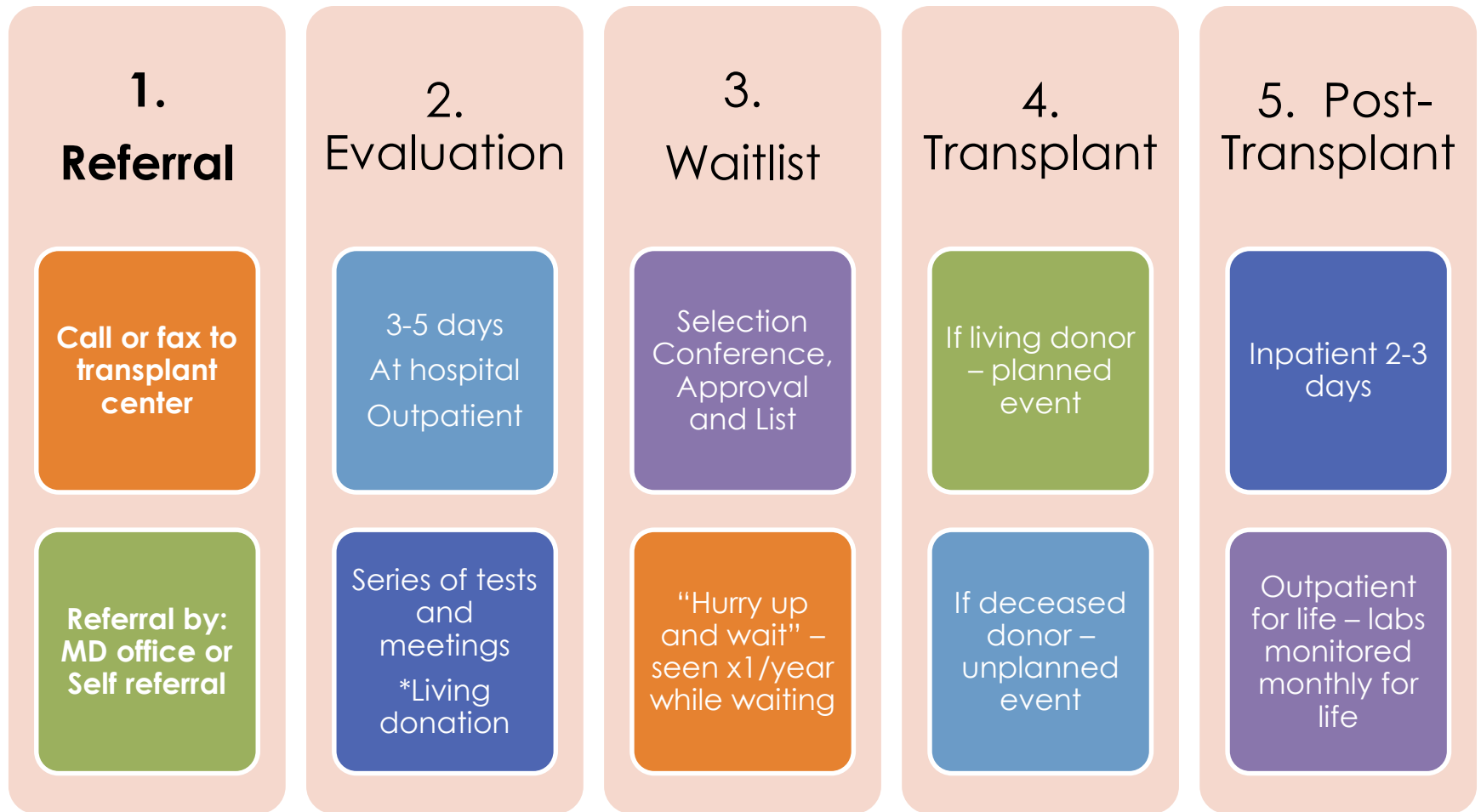
- Views expressed here are mine and do not necessarily represent those of my employer, University of California Davis.



Identify 5 Stages of Transplant



First stage - Referral



Referral Process

- Where the transplant journey begins
- Referral is made by:
 - General Nephrologist
 - Primary Care Physician (PCP)
 - Physician's office
- **Self-Referral.**

Information collected at time of referral:

- Name, address, date of birth, contact info and Chronic Kidney Disease (CKD) Stage
- Most recent labs:
 - Glomerular Filtration Rate (GFR)
 - Creatinine

Information collected at time of referral (continued):

- Current Height and weight
- Currently on dialysis? If yes:
 - Hemodialysis or peritoneal dialysis?
 - Exact date dialysis began?
- History & Physical (H&P) – most recent from your doctor

Connecting the Dots

After all information is received medical records are reviewed by Transplant RN Coordinator.

- 1. Is there anything that falls outside acceptance criteria.**
- 2. Are these things that can be changed?**



What's the difference?

Things that CAN be changed:

- Weight
- Compliance with medical treatment
- Drug use/abuse
- Availability of caregiver

Things that CANNOT be changed:

- Age
- Severity of cardiovascular disease



MB Tips – Referral

- **Timing is everything – the sooner you are educated and referred - the better.**
- **Assume all transplant centers accept self-referrals. Don't hesitate to make the call.** Call main number of hospital and ask to be connected to kidney transplant.
- **Get and stay organized – find a way that works for you.** You will be receiving a lot of information in the form of paper, mail and patient education materials.



Evaluation

1. Referral

Call or fax to
transplant
center

Referral by:
MD office or
Self referral

2. **Evaluation**

3-5 days
At hospital
Outpatient

Series of tests
and meetings
***Living**
donation

3. Waitlist

Selection
Conference,
Approval
and List

"Hurry up
and wait" –
seen x1/year
while waiting

4. Transplant

If living donor
– planned
event

If deceased
donor –
unplanned
event

5. Post- Transplant

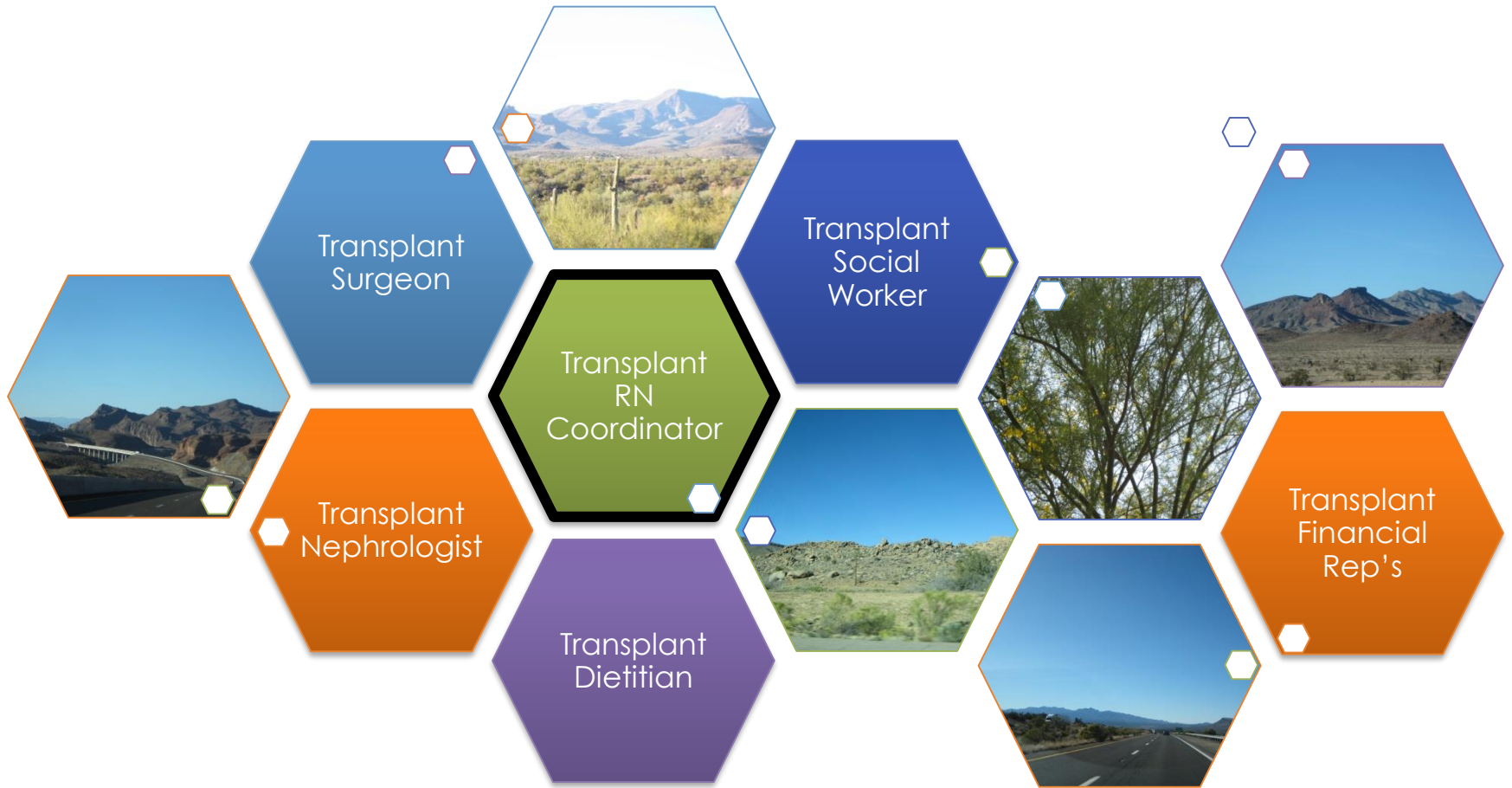
Inpatient 2-3
days

Outpatient
for life – labs
monitored
monthly for
life

Transplant Financial Coordinator

- Evaluation – can the patient be evaluated at this transplant center?
- Testing required while waiting
- Transplant procedure and inpatient stay (authorization for the event and associated costs)
- **Medication coverage including how much post-transplant medications are expected to cost post-transplant**

Meet members of the Transplant Team



Transplant Evaluation Tests and Appointments

- Ultrasound of abdomen
- Blood tests
- Urine tests
- Creatinine
- Chest X-ray
- ABO – Blood typing
- Tissue typing
- Transplant RN Coordinator
- Transplant Surgeon
- Transplant Nephrologist
- Financial Services Representative
- Transplant Social Worker
- Transplant Dietitian
- Transplant Pharmacist

Transplant Evaluation

- Transplant Evaluation lasts 2-5 days in outpatient setting with tests, appointments, education and labs.
 - **Education** is an important part of the Transplant Evaluation.
 - **Education** about *types* of kidney transplants:
 - living donor,
 - paired kidney donation,
 - deceased donor
 - **Education** about the *categories* of deceased donors:
 - High Risk Donors
 - Increased Risk ***new**
- Important** because you pick the ones from which you would consider accepting a donated kidney.



MB Tips - Evaluation

- **Bring your caregiver to transplant evaluation** (requirement at many centers).
- **Bring 2 notebooks and 2 pens to every appointment. One for you. One for caregiver.**
- Throughout evaluation – **record as much as possible for 2 reasons:**
 - Humans are more likely to remember things that are written in our handwriting.
 - That burning question you **KNOW** you will remember?

Studies show – you won't.

WRITE IT DOWN. You and your caregiver.



MB Tips - Evaluation

- **Bring snacks and drink(s)** in a small insulated cooler – the pace is quick with little down time.
- Lodging: **check to see if overnight lodging is available** for patients going through transplant evaluations.



Waitlist

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Self referral

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Getting to the Waitlist

Three steps:

- Selection Conference
- Approval to be added to UNOS wait list
- Living donor OR deceased donor

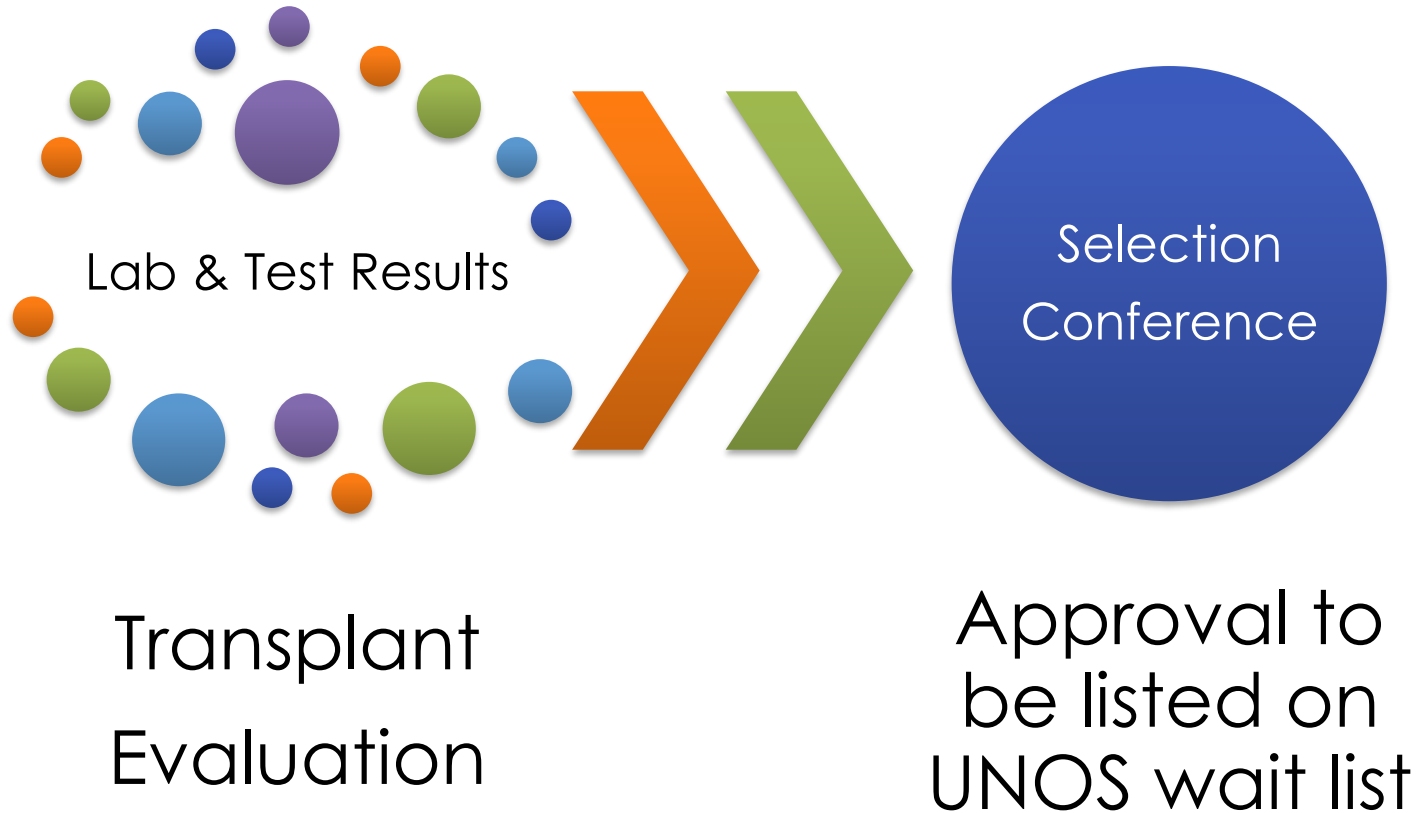


Selection Conference

- **Asks the question:**
 - **Does the risk of transplantation surgery outweigh the benefit for this patient?**



Getting to Waitlist Selection Conference



Living Donor vs. Deceased Donor

- **Living Donor**
- Planned event
- Scheduled as soon as you and donor are approved by Selection Committee.
- ***this is your best option.**
- **Deceased Donor**
- Unplanned event
- Depending on blood type and presence of antibodies, the wait for a kidney could be several years
- *“Hurry Up & Wait”*

What is best case scenario?

- **Living donor transplant *before* the need for dialysis.**
- ***Especially* for PKD patients.**



Criteria to be a Living Kidney Donor

- 18 years of age
- Good health
- Free of infection (Hep C, HIV)
- Free of cancer, uncontrolled high blood pressure, diabetes, heart disease, liver or lung disease.
- Not obese
- Not pregnant



Living Donor Criteria

- **Must be voluntary**
- Throughout donor evaluation – questions are asked by each health care professional
- Framed in different ways – all getting at the same question:
 - *Are you here voluntarily?*
 - *Are you being coerced in any way?*



Getting on the list at more than one center? Is that allowed?

- Yes – called Multiple Listing
- Acceptable for patients to be considered for organs that become available in other areas.
- Must be evaluated and listed at each center (because each center has slightly different criteria for acceptance).
 - **Obtain copies of all medical records regarding the Transplant Evaluation.**
- Is there a benefit to multiple listing?

Yes.



How Transplant Centers are alike

- A lot of rules issued by federal government:
 - United Network of Organ Sharing
 - CMS – Centers for Medicaid & Medicare Services
- Rules for transplant centers are very specific.
- **Result? A degree of similarity among all transplant centers**



Examples of How Transplant Centers are Different

- **Pre-Transplant**

- Listing criteria

- Variations in age criteria
- Variations in amount of risk willing to accept.
 - PHS High Risk
 - **PHS Increased Risk***



Examples of how Transplant Centers are Different

- **Surgery** – perform native nephrectomies at same time of transplant for living donor cases only.
- **Post-Transplant**
 - Medication management
 - Example: **steroid avoidance**
 - **Routine kidney biopsy** as part of protocol
 - Requirement to stay local after transplant
 - Ranges from 2 weeks – 6 weeks



Choosing a Transplant Center

- 258 Transplant Centers in the U.S.
- All must meet strict professional and regulatory standards.
- The difference between the best and worst transplant center in the U.S. is 3%.
- Geographic proximity often biggest factor



Transplantmodels.com

- **Tool published by Johns Hopkins to help you answer the important questions.**
- **It's free.**
- **You can access the information as easy as your doctors.**



Transplantmodels.com

Predicts the chance of survival for one alternative over the other.

Example: Should I accept a PHS High Risk kidney?

The actual question:

What is chance of survival if I accept a high risk donor kidney vs. staying on dialysis and waiting for another offer?



Understand the question:

What is my chance of survival on dialysis

vs.

my chance of survival receiving a kidney transplant.

Both come with risks.

*What is not fully appreciated: **dialysis is not risk free. Health erodes in direct correlation to how long a person is on dialysis.***



Waiting for Transplant

Things to do NOW

so you won't have to LATER

- **Get and stay organized** – keep a binder of your records to help you manage information – medical and financial.
- **Caregiver. Caregiver. Caregiver.**
Someone who has the time, health and flexibility to be your caregiver. Choose wisely.
- **Prepare a phone/e-mail tree** to make it easy for caregiver to provide updates.
- **Personal Affairs** – Advanced Directive, writing a will, sharing access to bank accounts, e-mails, blogs. FMLA paperwork, insurance and/or loan deferment paperwork.
- **Arrange for travel** when you receive “the call”.
- **Arrange for lodging** if traveling from out-of-town.



Waiting for Transplant

Prepare Practically

- **Take care of yourself**
 - The better your health at the time of transplant – the better your recovery will be after surgery.
 - Healthy diet, exercise and relaxation
- **Medical Care** while you are waiting
 - Primary – referring physician/nephrologist
 - Once a year to Transplant Center while waiting
- Keep the transplant team informed of **any changes in your health** or **changes in insurance**.
- **Contact information up-to-date** – make sure we can get in touch with you.



What to pack

- Clothing that fits loosely.
- Sleepwear
- Eye glasses
- Hearing Aids
- All medications
- Personal items: music, magazines, books, photos of family and friends.
- Change packed items seasonally as needed.
- Any monitoring equipment –
 - BP cuff,
 - BP monitoring machine,
 - sleep apnea equipment,
 - thermometer,
 - glucometer,
 - Scale.
- Decide what to pack – pack as much as you can ahead of time. Make a list of what to add when you receive the call.



Kidney Transplant

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Transplantation

- General Anesthesia
- Transplanted kidney is placed in lower abdomen.
- Blood vessels of the new kidney are joined to existing vessels in the groin area.
- With PKD patients, native kidneys not usually removed during the transplant surgery *however* more centers are offering as an option for living donor cases only.



Post-Transplant

- Inpatient 2-4 days
- Discharged – must stay close for 3-6 weeks
- Hospitality Village?
- Special Arrangements with local hotels?
- Outpatient
- Frequent labs at first to regulate immunosuppression meds

Online Resources

Transplantmodels.com

Transplantliving.org

Unos.org

Srtr.org



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