#### **Texas Health** Resources Kidney Transplant Orientation





- Know what each team member can do for you
- Learn about the transplant evaluation process and the risks and benefits of kidney transplant.
- Understand YOUR responsibility before, during, and after kidney transplant
- Find out what resources are available for transplant patients



#### **THFW Kidney Transplant Program Team Members**

#### **Kidney Transplant Main Office** 817-250-2443

Transplant Coordinators	817-250-2412
	817-250-3233
Department Assistant	817-250-2413
Scheduler	817-250-2665
Social Worker	817-250-2568
Dietitian	817-250-2653
Financial Coordinator	817-250-3245
Pharmacist	817-250-2443
Living Donor Patient Advocate	817-250-2843
	Texas Health Harris Methodist Hosp

FORT WORTH

#### **Kidney Disease Treatment**

- Kidney transplant is an alternative treatment option to kidney disease ~ not a cure
- Other treatment options include:
  - Hemodialysis (In-Center, 3 times per week)
  - Home hemodialysis
  - Peritoneal dialysis (at home via abdomen)
- Kidney transplant is not always the best option
- You have the right refuse evaluation and transplant



- Complete transplant orientation and sign consent
  - 6-minute walk, labs and testing may be completed during on-site orientation
- <u>Evaluation Appointment</u> (6 8 hours)
  - Labs (approximately 22 blood tubes)
  - Six-minute walk (Wear comfortable shoes)
  - EKG, Echocardiogram, Chest X-ray
  - Meet with Transplant Nurse Coordinator, Transplant Social Worker, Financial Coordinator, and Dietitian



- Evaluation Appointment (continued)
  - Second lab draw blood type confirmation
  - Transplant Surgeon assessment
  - Transplant Kidney Doctor (Nephrologist) assessment
  - Medication review with Transplant
     Pharmacist

We may request records from other facilities if tests were completed recently



- Additional testing may be required
  - CT scans
  - Carotid ultrasound
  - Nuclear stress test
  - Heart catheterization
  - Psychology consultation
- Health Maintenance Cancer Screening

   Age specific
   Texas Health



- Health Maintenance Screening required per American Cancer Society:
  - <u>Women</u>:
    - Pap smear (unless total hysterectomy)
    - Mammogram (over age 40)
  - <u>Men</u>:
    - Prostate evaluation (per physician request)
- ALL patients over age 45:
  - Colonoscopy



- Your evaluation must be completed in a timely manner, preferably in 2 – 3 months
- Completed evaluations will be presented to the Transplant Acceptance Committee (TAC)
- **TAC** is a multi-disciplinary team that includes the physicians, pharmacist, nurse coordinators, financial coordinator, social worker and dietitian



# **Transplant Evaluation Decision**

- The Transplant Acceptance Committee (TAC) determines candidate eligibility for transplant listing based on all information obtained during evaluation
- The benefit of transplant must outweigh the risk involved for individual patients. Financial, social and medical circumstances are considered at the time of decision.
- You will be notified of the committee decision by certified letter.

### **Transplant Evaluation Decision**

- TAC decisions:
  - <u>Approved</u>: List as either Active (Status 1) or as Inactive (Status 7)
  - Declined: Transplant is not a safe option
  - <u>TAC Hold</u>: A decision is pending the completion of additional actions



# Waiting List Status

• Listing status for a candidate on the wait list

#### - Status 1, Active:

Ready to receive potential organ offers

#### - Status 7, Inactive:

Temporary hold pending completion of testing, or resolution of an identified concern (insurance change, illness, etc.)

 A candidate may be <u>de-listed</u> if transplant is no longer a safe treatment option

# Waiting List

- Once approved to be listed for transplant, you can:
  - Be registered on more than one wait list at different transplant hospitals
  - Transfer primary waiting time to transplant facility of choice
  - Transfer care to a different transplant hospital without losing accrued waiting time points
- Make sure you can be reached by phone 24 hours a day, the call for transplant can come at any time



# **Waiting List Reminders**

- Update your Transplant Coordinator with any changes in your health status, insurance, social support, or contact information
- Changes in your condition may prevent transplant surgery at the time of an offer
- Changes in your insurance coverage may incur additional costs to you



# Waiting List

- Average wait time for a deceased donor kidney transplant is 3 to 5 years, nationally.
- Annual re-evaluations are required to maintain ACTIVE listing status until you receive a transplant.
- Active listing status does not guarantee you will receive a kidney transplant



# Waiting List

- Active transplant candidates are required to have scheduled blood draws for antibody testing (Panel Reactive Antibodies - PRA)
- **PRA** determines what donor antigens are unacceptable by your immune system.
- If you are on dialysis, your dialysis center will collect the specimen. If you are not on dialysis, contact our office when you receive the PRA kit.
- Stay Healthy and Active!!



# **Kidney Allocation**

- The new kidney allocation system (KAS) began in December, 2014 to ensure the best use of all donated kidneys using the statistical tools of KDPI and EPTS
  - Kidney Donor Profile Index (KDPI) estimates how long a donated kidney is expected to remain functional in a recipient
  - Estimated Post Transplant Survival (EPTS) estimates the years of survival post transplant for a recipient

# **Kidney Allocation**

- All transplant centers place approved candidates on the <u>national wait list</u>
- Before an organ is allocated, all candidates on the wait list that are incompatible with the donor because of blood type, height, weight and other medical factors are automatically screened from any potential matches
- Then, the computer application determines the order that compatible candidates will receive offers, according to national policies

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# **Kidney Allocation**

- Blood type and other medical factors weigh into the allocation of every donated organ.
   Additional factors are unique to kidneys:
  - Waiting time time accrues from dialysis start date,
     <u>or</u> date of listing, if not on dialysis.
  - Donor and recipient immune system incompatibility (cPRA) (determined by PRA testing)
  - Pediatric status
  - Prior living donor
  - How far from donor hospital
  - Survival benefit (EPTS)



### **Organ Offer Assessment**

- The transplant surgeon reviews each organ offer matched with our candidates to assess the quality of the kidney
- Not all organ offers are viable to transplant
- When one of our listed recipients become primary (top of the list) for an offer, AND the kidney is of good quality, the surgeon instructs the coordinator to call our first patient on the match run.

# **Organ Offer Assessment**

 If the kidney organ offer is determined to be of poor quality, our surgeon will decline for our candidates, and the next patient on the national list will become primary for that organ

• Every organ offer is different!!!



# Calculated Panel Reactive Antibodies (cPRA)

- Candidates that are highly sensitive to donor antigens receive priority points on the wait list
- The higher your Calculated Panel Reactive Antibodies (cPRA), the more difficult it is to match a donor
- Candidates with a cPRA of 98, 99, or 100 percent receive national priority, as they are very difficult to match a local donor
- It is important to complete your PRA labs so wait list information is current.

# **Kidney Donor Profile Index**

- Kidney Donor Profile Index (KDPI) is calculated based on information about the deceased donor
  - Age Height Weight Ethnicity
     History of Hypertension History of
     Diabetes Cause of Death Serum
     Creatinine Hepatitis C Virus (HCV) Status
     Donation after Circulatory Death (DCD)
     Status



# **Kidney Donor Profile Index**

- The **KDPI** ranges from 0% to 100%
  - Lower KDPI values are associated with higher expected post-transplant function time
  - Higher KDPI values are associated with lower expected post-transplant function time
  - Time of function is not guaranteed for any organ



# **Kidney Donor Profile Index**

- KDPI of 85% or less is considered a standard donor kidney with function time averaging 10 years
- KDPI greater than 85% is considered an expanded criteria donor kidney with function time averaging 5.5 years
- Patients will return to dialysis treatment when the transplanted kidney is no longer functioning and may qualify for re-transplant



# **Identified Risk Donor**

- <u>Donors with identified risk</u> for possible transmissible disease according to Public Health Service guidelines
  - IV drug use or sex with an IV drug user
  - Sex with an individual known to have a transmissible disease
  - Male sex with male (MSM)
  - Prostitution
  - Jail time greater than 72 hours within the last 30 days
  - Donor with no available medical/social history



# Estimated Post Transplant Survival

- Estimated Post Transplant Survival (EPTS)
  - This number is used to match about 20% of kidneys. Every adult patient on the kidney waitlist receives an EPTS score. EPTS scores are percentages that range from 0% to 100%
  - <u>Factors</u>: candidate age, length of time on dialysis, prior transplant of any solid organ, and diabetes status



# Estimated Post Transplant Survival

Candidates with a *lower* EPTS score are expected to experience *more* years of function from a transplanted kidney compared to candidates with higher EPTS scores.

 The EPTS score is designed to achieve better longevity matching. Younger candidates with longer life expectancy qualify for kidneys with longer estimated time of function (low KDPI)



# Scientific Registry of Transplant Recipients (SRTR)

- The Scientific Registry of Transplant Recipients SRTR is a national database of organ transplant statistics
- Transplant outcome data is collected, analyzed and published for every transplant center in the U.S.
- Statistics are updated every six months.
- You may compare outcomes for any transplant center with national statistics on their website at <u>http://www.srtr.org/</u>
- If you need help accessing or interpreting the data, your nurse coordinator can assist you.



### **Transplant Day**

 When your big day arrives, you will receive a call from the on-call transplant coordinator

<u>Note</u>: The call **may not** come from a local number, so be sure to answer ALL phone calls while you are on the waitlist.

- You will be asked a series of questions to ensure it is safe to proceed with transplant
- After admission to the hospital, a final cross check is done between you and the donor (cross-match takes 5 hours minimum)



### **Transplant Day**

- Pre-operative assessment by doctors
- Blood work
- EKG and CXR
- Sign consents
- Anti-microbial skin prep (shower)
- Dialysis (if not within 24 hours)
- Cross-match is negative—ready for surgery



### **Transplant Day**

- Surgery is approximately 3-4 hours
- Recovery in Intensive Care Unit (ICU) then transfer to Transplant Unit until discharge
- Education for you and support persons
- Obtain and pay for post-transplant medications (6-10 meds)
- Total hospital stay averages 4 10 days



# **After-Transplant Expectations**

- Regular follow-up visits with the Transplant Team are required immediately after discharge from the hospital
  - Two times a week for the first month
  - Every Monday and Thursday. These visits are a minimum of 4 hours long.
  - Clinic visits will gradually decrease over time
  - Your Transplant Team will let you know when you can start coming once a year
- Blood work will be required for each office visit



### **Nurse Transplant Coordinator**

The Nurse Transplant Coordinator will oversee a patient's journey throughout the referral, evaluation, transplant, and post-transplant phases





# **Transplant Coordinator**

 It is important to stay in close contact with your coordinator



- Keep your phone number and address current. Notify your coordinator of any changes
  - You may call your coordinator with any questions
- Contact your coordinator if you are sick or have been in hospital

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# **Transplant Coordinator**

- Roles and responsibilities:
  - PRE and POST transplant care
  - Medical and psychosocial evaluations
  - Patient education
  - Assistance and appeal (patient advocate)
  - Inpatient and outpatient clinic
  - Living donation process
  - -24 hour emergency access (post transplant)
  - Organ offer review
  - Wait list management



## **Transplant Social Worker**

The role of the Transplant Social Worker is to help the patient and their family manage a variety of issues associated with transplant





## **Psychosocial Evaluation**

Your evaluation by the social worker will include:

- A psychosocial history
- Analyzing your strengths, support system, and other resources
- Identifying problem areas and provision of community resources or referrals
- Determining eligible primary caregivers and transportation providers after transplant



## **Psychosocial Evaluation**

- The psychosocial evaluation will help determine if a transplant candidate has the appropriate stability, motivation, and support system to meet the challenges of transplantation
- The use of tobacco, alcohol and/or illicit drugs is carefully examined
- Patients with alcohol and drug dependence may require therapeutic intervention and should demonstrate abstinence before listing



# **Support System**

- It is required that you have a primary support person and a backup support person
  - The primary support person must be able to:



- Come to your evaluation appointment
- Meet with our social worker
- Agree to the support contract terms
- Support persons can be family or friends



# **Support System**

- A strong support system is critical to the success of a kidney transplant.
- The qualified support person will need to
  - Drive you to clinic appointments immediately following discharge from the hospital
  - Learn the signs and symptoms of infection and rejection
  - Help manage your pill box
  - Document your vital signs, drain output, and blood sugars
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# **Support Group**



- A support group is recommended for transplant patients, their families, and friends
  - The education and fellowship is meaningful during all phases of the transplant process, including evaluation, waiting for transplant, time of transplant, and after transplant.
    - Contact your social worker for current, available resources.



## Transplant Financial Coordinator

The role of the Transplant Financial Coordinator is to determine a patient's financial eligibility for transplant





#### **Patient Financial Responsibility**

- Provide a copy of all insurance and pharmacy cards to our office
- Obtain a secondary insurance plan to help cover the cost of copays, deductibles, and co-insurance
- Enroll in Medicare Parts A, B & D (Part D is optional if you have a group health plan through your employer)
- Develop a financial plan after meeting with our financial coordinator



#### Before Transplant

- Evaluation testing:
  - If <u>Medicare</u> is primary coverage, evaluation costs are billed to the transplant program
  - If you have <u>third party (private) insurance</u> coverage, evaluation costs are billed to your insurance
- Should you require *treatment* as a result of the testing, further charges would be billed to your insurance, and you would be responsible for the balance

-You are responsible for:

- <u>Health Maintenance and Screening Cost</u>: Pap-smears and mammograms for women, colonoscopy for those over 45, and vaccinations
- Non-Medical Costs:

This may include, but not limited to, travel, lodging, meals, lost wages, parking, and childcare

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- Hospital Admission for Transplant
  - A kidney transplant could cost more than \$200,000 depending upon the length of stay
  - Your deductible, co-insurance, and maximum out of pocket expenses will be determined by your insurance coverage
  - You must pay for your medications at the time of discharge

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#### After Transplant

- Medicines can cost \$25 to \$500 or more per month
- All follow-up care and testing will be billed to your insurance company
- You should be prepared to return to work
   <u>before</u> losing your SSDI and/or Medicare, unless you are over the age of 65, *OR* you have another disability
- Your Financial Coordinator will inform you of the financial costs and insurance benefits associated with your transplant



## **Transplant Dietitian**

The role of the Transplant Dietitian is to ensure patients understand their individualized eating plan and to make healthy goals





# Nutrition After a Successful Kidney Transplant

- In most cases, you will be able to eat foods high in potassium again like melons, tomatoes, oranges, bananas, and baked potatoes
- Foods high in phosphorous like red beans, milk, ice cream, and peanut butter are encouraged
- You will need to keep your new kidney well hydrated with extra fluids (2-4 liters of water), especially for the first several weeks after transplantation

# Nutrition After a Successful Kidney Transplant

- Watch your weight by monitoring calorie intake and non-strenuous physical activity
- Anti-rejection medicines given after transplant can cause increased appetite, weight gain, and could make diabetes more difficult to control
  - About 15% of patients will develop diabetes after transplant, even though they never had it before.
     Diabetes education is given at the time of transplant. All recipients must learn to check blood sugar 4 times per day after discharge from the hospital.



# If you already have Diabetes

- Be prepared to take insulin every day and test your blood sugar up to 4 times a day
- You will receive a blood sugar monitor, if you do not already have one
- Your support person should be able to learn about giving insulin and blood sugar testing after transplant



### **Transplant Pharmacist**

### The role of the Transplant Pharmacist is to educate patients about their medicines





## Medicines

- After kidney transplant, you will take antirejection (immunosuppression) medicine for the life of your transplant
- You must take this medication as recommended by the Transplant Team
- Always contact your coordinator before taking any new medication not prescribed by the Transplant Team – including over-the-counter (OTC) medicine
- Do not take any herbal products



### Medicines

- Always plan ahead! --- Request prescription refills at least 2 weeks before running out of the medicine
- If you travel after transplant be sure you have more than needed for your trip in case you get stranded
- **Never** skip your medicines, even if you are sick
- If the medications make you sick, call and speak with your transplant coordinator about your symptoms

## **Medication Side Effects**

- Common anti-rejection medicine side effects:
  - Higher risk of infections
  - Weight gain
  - Post-transplant diabetes
  - Tremors
  - Insomnia
  - High blood pressure
  - Loose stools



#### Anti-Rejection (Immunosuppression) Medicines After Transplant

- Prograf®
- Myfortic® or Cellcept®
- Prednisone® (Steroids)
- Sirolimus® or Everoliumus®



- **Do Not** take these "over-the-counter" medicines:
  - NSAIDS- Aleve® (Naproxen)
  - Advil®/Motrin®/Midol®/Nuprin™ (Ibuprofen)
- **Do Not** take these prescription medications:
  - Indocin®
  - Celebrex®
  - Toradol®
  - Naprosyn®



### **Patient Resources**

- United Network for Organ Sharing/OPTN

   https://optn.transplant.hrsa.gov/
- Texas Kidney Health

- www.txkidney.org

- Transplant Support Groups
  - https://www.transplantliving.org/community/supportgroups
  - Renal Support Network https://www.rsnhope.org



### **Patient Resources**

- Centers for Medicare and Medicaid Patients

   http://cms.hhs.gov
- National Kidney Foundation

   https://www.kidney.org/
- International Transplant Nursing Society

   https://www.itns.org
- Scientific Registry of Transplant Recipients

   https://www.srtr.org
   https://www.srtr.org



# Questions

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