



# **Transplant Candidate Education Program**

**Renal and Pancreas Transplant Division**

**Robert Wood Johnson | RWJBarnabas**  
**University Hospital HEALTH**



# Transplant Candidate Education Program

*This document is intended to supplement the education that you received today during your evaluation visit.*

*The Transplant Candidate Education Program was developed to fully inform you about the evaluation process to receive a kidney transplant from a living donor or to be placed on the waiting list for a deceased donor organ. The selection criteria (the things that would qualify or disqualify you for a transplant) were discussed with you. The risks and benefits of organ transplantation and information about the surgical procedure were also reviewed. In addition, alternative treatments, your rights as a transplant recipient, and insurance and confidentiality issues were discussed. The following information will outline what you have learned in the Transplant Candidate Education Program.*





## Overview

### A. Participation

Your participation in this evaluation process is completely voluntary. You are free to withdraw from the evaluation process at any time. In addition, if and when you are found eligible for a transplant, you have the right to refuse transplantation at any time, including when you are called in to receive a transplant.

### B. Treatment Alternatives

Persons with kidney failure have several options:

1. Dialysis: Hemodialysis or Peritoneal Dialysis
2. Kidney Transplantation – Kidney may come from a:
  - a. Deceased donor kidney
  - b. Living donor kidney (See Section – Living Donation Options – Pg 8)
    - (i) Compatible Donor
      - (A) Related: blood or genetically related
      - (B) Unrelated: emotional connection (e.g., spouse, in-law, friend) or in some rare instances, an altruistic living donor who is unknown to you
    - (ii) Incompatible *Donor Living Donor Kidney Exchange Program*: for recipients with medically acceptable living donors who are incompatible by blood type or crossmatch, recipient donor pairs are entered into a registry for an exchange match.

### C. Recipient Benefits

According to the most recent United Network for Organ Sharing (“UNOS”) Scientific Registry for Transplant Recipients data:

1. On average, patients who receive a kidney transplant have significantly increased life expectancy compared to patients who are maintained on dialysis while waiting for a kidney.
2. Most transplant recipients report an enhanced quality of life through improved health and energy. You can travel, return to work regular hours and/or go back to school.
3. These benefits may vary depending on the age and other medical conditions of the transplant recipient.



## Additional Information

The following organizations and associated web sites provide general information, frequently asked questions and patient testimonials about kidney transplantation:

**www.srtr.org.** – Scientific Registry for Transplant Recipients publishes updated data on national and center specific outcomes for organ transplantation. Generally, this is updated every six months.

**optn.transplant.hrsa.gov** – The Organ Procurement and Transplantation Network (OPTN): The unified transplant network established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984.

**www.unos.org** – United Network for Organ Sharing (UNOS): The organization contracted to administer the OPTN. UNOS has also developed a website specifically for patients and families at [www.transplantliving.org](http://www.transplantliving.org) (For Spanish version, the website is [www.transplantesyvida.org](http://www.transplantesyvida.org)).

**www.njsharingnetwork.org** – The Sharing Network: The non-profit, federally certified organ procurement organization (OPO) of New Jersey. An OPO is a program that acquires and coordinates placement of donated organs for patients on national transplant waiting lists.

**www.kidneyfund.org** – American Kidney Fund (AKF).

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

**www.kidney.org** – National Kidney Foundation.

**www.rwjuh.edu** – Robert Wood Johnson University Hospital Kidney/Pancreas Transplant Center

## The Evaluation Process

### A. Eligibility/Ineligibility

The evaluation process determines if you are medically eligible to receive a kidney transplant and also includes an assessment to make sure that there are no psychological or social barriers to transplantation. The goal of the evaluation process is to make sure that your health status is optimal and that you can be safely transplanted. If a new health problem is found during the evaluation, you may be referred back to your nephrologist or the appropriate medical specialist. If a serious health problem is found or if there are psychological or social barriers that cannot be resolved, it is possible that you may not be able to receive a transplant.

Your Transplant Coordinator will work closely with you to ensure that your evaluation is completed as quickly as possible. This should take no longer than 90 days in most circumstances, and many times the evaluation can be completed in much less time. If you do not complete your testing within this time frame, your Transplant Coordinator will try to determine the reasons for the delay and try to help you complete your evaluation. If you do not complete your evaluation, despite multiple attempts to contact you or assist you to do this, your case may be closed for lack of responsiveness.

If you are being evaluated for a pancreas transplant, either simultaneous kidney-pancreas (SPK), a pancreas alone, or pancreas after kidney (PAK), you will follow the same evaluation process. However, additional testing may be needed to determine your eligibility for this surgery.

A body mass index  $> 30\text{kg/m}^2$  which is a measure of obesity is often a contraindication to pancreas transplant. If a reduction in body weight is required, our dietitian can work with you to reach the weight loss goal.

### B. Group Education Session

The Group Education Session included a discussion of the following topics:

- ▶ Selection criteria (conditions or factors that qualify or may disqualify you from receiving a transplant)
- ▶ Testing requirements needed for medical clearance



- ▶ Tissue-typing and cross matching
- ▶ How the wait list works, including multiple wait listing and transfer of wait time
- ▶ Living and deceased donor organs: types and issues specific to each type
- ▶ Explanation of the Kidney Donor Profile Index (KDPI) and Donation after Cardiac Death
- ▶ What happens when an organ becomes available
- ▶ Overview of the transplant surgery
- ▶ The general hospital experience
- ▶ Common immunosuppressant medications and their side effects
- ▶ Post-Transplant Care - visits to the transplant clinic
- ▶ Possible transplant complications, such as rejection and infection
- ▶ Financial considerations
- ▶ Healthy lifestyle following transplantation



### C. Individual Evaluations

The following individual evaluations are also part of the evaluation process:

- 1. Nursing Assessment**
  - a. Review of health status and required laboratory and diagnostic testing
  - b. Education/discussion about the option of living donation
- 2. Physician Evaluation**
  - a. History and Physical
  - b. Education/discussion including:
    - (i) risks and benefits of transplantation
    - (ii) option of living kidney donation
- 3. Social Work Assessment**
  - a. A thorough discussion of your psychological and social history, employment and rehabilitation post-transplant.
  - b. A review of your social support system as it relates to post-transplant care and assistance with activities of daily living, medications and transportation to clinic appointments as needed.
  - c. Review of compliance with your current medical regimen (including adherence with dialysis treatments, medications, dietary restrictions, bloodwork and laboratory testing, etc).
  - d. A discussion of your reasons for wanting to become a transplant recipient.
  - e. A discussion of the psychosocial risks including possible emotional, financial, and physical stressors that receiving a transplant may pose to you and your family.

- f. Education/discussion about the option of living donation.
- g. Review of high risk behaviors (i.e. tobacco, alcohol and illicit substances) and how these behaviors may impact the success or failure of transplantation.

#### **4. Nutrition Assessment**

- a. Nutrition assessment and education aimed at achieving and maintaining optimal nutritional status for transplantation.

#### **5. Financial Assessment**

- a. Review of how to finance your transplant, current insurance status and financial responsibilities (co-pays/deductibles etc) and issues that may affect your ability to obtain insurance in the future.

### D. Overview of Requirements for Medical Clearance

#### **1. Basic Testing (within the last 12 months)**

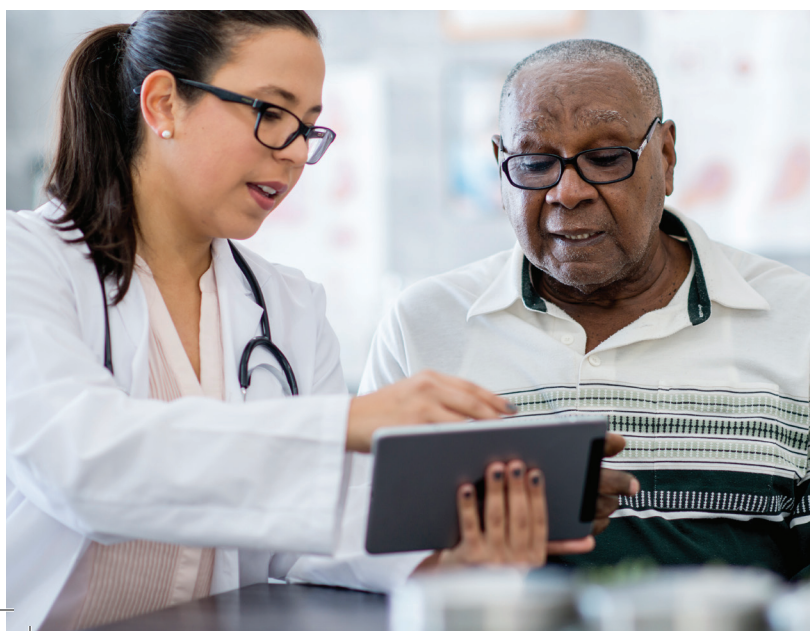
- a. Medical History and Physical –
- b. Chest X Ray
- c. Electrocardiogram (EKG)
  - (i) Lab work- 2 separate ABO-blood typing, various serologies: Hepatitis B and C, and HIV
  - (ii) Medical Evidence Report (MER) from your dialysis unit – if you are on dialysis

#### **2. Cancer Screening**

- a. Colonoscopy for patients over 50 years old
- b. Prostate Specific Antigen (PSA) for men over 45 years old
- c. PAP smear for all women
- d. Mammogram for women with family history of breast cancer and/or over 40 years old

#### **3. Cardiac Testing: Nuclear Stress Test, Echocardiogram and Coronary Angiogram may be required for patients with any of the following:**

- a. Abnormal Electrocardiogram (EKG)
- b. History of hypertension
- c. History of diabetes
- d. History of cardiac problems such as heart attack, angioplasty, stent placement, bypass surgery, valve replacement





- 4. CT of Abdomen /Pelvis
- 5. Other testing that may be required based on your medical history:
  - a. Blood clotting tests
  - b. Lung Function Tests
  - c. Ultrasound of liver/kidney
  - d. Peripheral Vascular studies
  - e. Others as recommended by transplant physician or required by your insurance company

### E. Recipient Selection Criteria

Any adult patient with Chronic Kidney Disease (CKD) with a GFR <20 mL/min, either on or approaching dialysis, may be considered for kidney transplant. Candidates must have successfully completed the evaluation process including medical and psychosocial clearance. The transplant team then makes a decision regarding your suitability for transplant based on the established selection criteria and the results of required testing. In order to remain active on the list, you will be re-evaluated periodically and must continue to meet the established criteria.

Absolute contraindications or disqualifying conditions for kidney transplant may include, but are not limited to:

- ▶ Severe Coronary Heart Disease
- ▶ Severe Heart Failure
- ▶ Severe Peripheral Vascular (Blood Vessel) Disease
- ▶ Severe psychiatric illness, uncontrolled with medication
- ▶ Untreated psychiatric condition(s), including suicide risk
- ▶ Chronic infections (unresolved)
- ▶ Advanced Pulmonary (Lung) Disease
- ▶ Advanced Liver Disease
- ▶ Advanced Cancer
- ▶ Chronic proven non-adherence with medication and/or prescribed treatment(s)
- ▶ Active Substance Abuse or treated substance abuse with a high risk of relapse
- ▶ Morbid Obesity with poor functional status
- ▶ Age 80 or older (Age 70-80 must have a living donor and meet clinical criteria)

- ▶ Absence of funding for transplant procedure, hospital charges and/or medications
- ▶ Poor social support, including absence of confirmed family caregivers during the immediate post-transplant period.
- ▶ Multiple medical conditions and/or psychosocial risk factors which, in combination, would make transplantation too high risk for you
- ▶ Residency status may preclude listing for deceased donor transplant

### F. Yearly Updating of Tests

Your transplant coordinator will inform you which tests need to be updated yearly and will help you with this requirement. It is your responsibility to make sure your testing is up to date.

### G. Tissue Typing Overview:

1. Blood Group compatibility:

	Recipient	Compatible Donor:
Blood type	A	A or O
Blood type	B	B or O
Blood type	O	O
Blood type	AB	A or B or AB or O

2. Blood Type Incompatible Deceased Donor Transplant

Blood type B is an uncommon blood type so patients with blood type B wait the longest to receive a transplant. Some patients with blood type B may be eligible to receive a kidney from a blood subtype Non-A1 or Non- A1B deceased donor. The risk factors of this type of transplant include a slight increased risk of rejection, infection and loss of the transplanted kidney. Also this type of transplant may require additional therapies at the time of transplant to help prevent rejection. All blood type B patients will be reviewed for eligibility and educated for enrollment if they qualify for this option.

3. Tissue Typing and Cross matching
  - a. Tissue typing is done to determine your genetic markers (or your HLA – Human Leukocyte Antigens).
  - b. Panel Reactive Antibody (PRA) measures whether you have formed antibodies to other people’s HLA as a result of previous blood transfusions, pregnancies, or transplantations.



- c. Cross matching is the most important test to determine compatibility. Blood is mixed from the potential recipient and the potential donor.
- (i) A “positive” crossmatch means there was a reaction upon the mixing of the bloods. The donor and recipient are incompatible. Incompatible pairs may be eligible for *Living Donor Kidney Exchange and/or Program for Incompatible Transplants*
- (ii) A “negative” crossmatch means there was no reaction and the recipient and donor are compatible.

## H. Getting Listed

To become listed, you must complete all of the evaluations and diagnostic tests required and be cleared by the members of the interdisciplinary transplant team. You will be sent an official letter from your transplant coordinator informing you of the date of your listing and your status on the transplant waiting list. In addition, your nephrologist and your dialysis unit (if applicable) will be notified.

- ▶ **Active Status** – (Status 1) means you are ready to be transplanted at any time. Your testing is up to date and you are healthy despite your renal failure.
- ▶ **Inactive Status** – (Status 7) means you are not ready to be transplanted at this time for some reason such as illness, surgery, out of date tests, out of town traveling, getting treatment for hepatitis C, receiving cancer treatment, etc. This is a temporary situation until the issue is resolved.

## I. Monthly Blood Specimen

Once you are active on the transplant waiting list, one red top tube of blood must be sent to The Sharing Network on a monthly basis. If you are on dialysis, your unit can send this in for you. If you are not on dialysis, you must have this tube drawn every three months and sent directly to the NJ Organ and Tissue Sharing Network (NJOTSN). Your transplant coordinator will teach you exactly how to fulfill this very important responsibility. If a current blood tube is not at NJOTSN at the time a deceased donor kidney is identified for you, you may lose the opportunity to receive that kidney.

It is important to know you are still listed when you are inactive. You continue to accrue time but you will not be offered a kidney. During this inactive time, you will NOT need to have your monthly blood work drawn. Please communicate this with your dialysis nurse.

Your health status may change over the years especially if you are on dialysis. Therefore, you will be required to see us for re-evaluation appointments at regular intervals. Depending on your cause of kidney failure, age, or cardiac history you may come every one to two years. You may not need the same tests done with each subsequent visit, or you may need different testing than required in prior evaluations.

## J. How the Wait List Works

Each deceased donor kidney offered gets a score called Kidney Donor Profile Index Score or KDPI. The KDPI refers to how long a kidney is likely to function when compared to other kidneys. The KDPI is calculated based on facts about the donor that affect how long the kidney is likely to function. These factors include:

- ▶ Age
- ▶ Stroke as cause of death
- ▶ Height
- ▶ Weight
- ▶ Ethnicity
- ▶ Exposure to the Hepatitis C virus
- ▶ History of diabetes
- ▶ History of high blood pressure
- ▶ Serum creatinine (measure of kidney function)
- ▶ How donor died (brain death or loss of heart function)

Each transplant candidate will also get a score called Estimated Post Transplant Survival Score or EPTS. The EPTS is a % score ranging from 0 – 100 and refers to how long the candidate will need a functioning kidney transplant when compared to other candidates. The lower the EPTS, the longer the candidate will need a functioning transplant compared to other candidates. The EPTS is calculated based on facts about the candidate that affect how long you are likely to need a kidney; again, compared to other candidates.



These factors include:

- ▶ Age
- ▶ Length of time spent on dialysis
- ▶ Having received a previous transplant
- ▶ Current diagnosis of diabetes

How will KDPI and EPTS scores be used to allocate organs? Kidneys with a KDPI score of 20% or less will first be offered to patients likely to need a transplant the longest, those with an EPTS of 20% or less. Kidneys with a higher KDPI will be offered to patients with a higher EPTS.

When a deceased donor organ becomes available, the donor and any possible recipients must be blood group compatible, unless the recipient is enrolled in a blood type incompatible deceased donor program. A list of potential blood group compatible recipients is generated based on a point system. The points are allocated based upon calculated waiting time, quality of match, high recipient PRA (Panel Reactive-Antibody) and pediatric recipient status. If you are on this list of potential recipients, you will receive a phone call from a transplant coordinator. To be considered for this kidney you must be medically stable with no active infections and have your monthly

blood specimen at NJOTSN. You will receive detailed information and instructions from the transplant coordinator. Every available deceased donor kidney generates a different list of potential recipients. Therefore, there is no way to tell your “position on the list” until a particular kidney becomes available.

Under Organ Procurement and Transplantation Network (OPTN) policy, you can list at more than one transplant center (multiple-list). As with any transplant listing, you must be evaluated and accepted by a transplant center. You should also check with your insurance provider to see if there are costs associated with multiple listing that may not be covered. In addition, you would need to maintain current lab results and contact information for each transplant program where you are listed. The local Organ Procurement Organization in NJ is the NJ Sharing Network, which is responsible for the local NJ list. All hospitals in NJ that perform transplants are part of the same local list. Therefore, it will not benefit you to list at more than one hospital in NJ. You should consider going out of state.

Each patient will be provided with a pamphlet entitled “Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer” for detailed information pursuant to OPTN and UNOS policy.

## K. Living Donation Options

If you have a willing living donor, he/she may contact a member of the LD Team to express their interest in donating to you. Once it is determined that you are a candidate for transplant, your donor will be contacted by a LD coordinator to begin education and the evaluation process.

If you do not have a willing living donor but are interested in the option of living donation, the transplant team can provide guidance to you and resources that may help you to find a living donor. It is important for you to understand a few simple guidelines surrounding the use of social media or advertising for a living donor.

- ▶ The RWJ Transplant team reserves the right to decline donors solicited from certain websites or organizations, such as those that charge money for access to living donors.





- ▶ The use of Craigslist or other similar sites is strongly discouraged as these tend to attract people who live very far away and have no connection to you or your family. Therefore, it is difficult for the Living Donor Team to determine the motivations of potential donors who are solicited in this way.
- ▶ All donors who are altruistic to you (do not know you or do not share an emotional connection with you) must be evaluated at Robert Wood Johnson Transplant Center.
- ▶ Potential donors living outside of the United States must be related to you.

The following describes the many living donation options available to our patients:

#### 1. Living-Related Donor Transplantation

Living donors who have a genetic relationship with the recipient are called living-related donors. Donor/recipient pairs who share a close genetic relationship tend to have improved compatibility upon testing. Identifying a donor who has a strong genetic relationship with the recipient can lessen the chance of rejection of the new kidney.

#### 2. Emotionally-Related Donor Transplantation

Kidneys for transplant can also come from living unrelated or emotionally-related donors if immediate family members are unable to donate. Some examples of common emotionally-related donors are a spouse or close friend.

#### 3. Altruistic Living Donation

- ▶ **Directed Altruistic Donor** is a person who has some knowledge of the recipient (for example, through membership in a church/synagogue or via a mutual acquaintance). Thus, the directed altruistic donor is directing their donated kidney to this recipient.

- ▶ **Non-directed Altruistic Donor** is a person who wishes to donate to a person they do not know, either through donation to a recipient on the waiting list or through a Kidney Exchange.

While all donors are considered “altruistic” by nature of their gift of life, the two types of donors described above have no genetic or emotional relationship with their recipient. Their evaluation typically requires a slower pace, which allows them more time to reflect upon their decision to donate.

#### 4. Compatible Share Program

There may be times when a compatible donor/recipient pair may be offered the opportunity to participate in a kidney exchange. A compatible donor and recipient may choose this option because it provides the following:

- ▶ A chance to improve the recipient’s long term outcome. For example, the recipient may be able to receive a younger donor kidney or a better matched kidney.
- ▶ An altruistic opportunity for the compatible pair, because their participation in a kidney exchange would allow one or more incompatible recipient/donor pairs the opportunity to be transplanted.

#### 5. Living Donation Kidney Exchange Program

Many individuals have willing kidney donors that are incompatible by blood type or cross-matching. This program involves the matching and exchange of kidneys between donor/recipient pairs that are compatible with each other.

### L. Deceased Donors

1. Deceased donor organs are obtained from individuals after their death whose next of kin has given permission to have their organs donated.
2. Deceased donor organs are most often from persons with brain death. Brain death means that there is no brain function but the heart is still beating so that the blood supply is still flowing to all of the body’s organs. Deceased donor organs may also come from non-heart beating donors. This means the organs were donated after cardiac death has occurred. This is referred to as donation after cardiac death (DCD). Cardiac death means the patient is without oxygen and the heart has stopped beating.
3. At the time an organ becomes available, the transplant coordinator will provide you with general information about the deceased donor organ such as age of the donor, sex, cause of death, as well as any known risk factors (discussed below). Before deciding to accept the donor organ, you may wish to speak to the transplant physician on-call, if there are any additional concerns or questions. The risks and benefits of accepting

the donor organ will be reviewed with you at the time of admission by the transplant physician.

4. Remember, you have the right to refuse a deceased donor organ offer at any time.

## M. Organ Risk Factors

1. Organ risk factors that could affect the success of the transplant or the health of the transplant recipient include but are not limited to, the donor's history, the condition or age of the organ used, and/or the recipient's risk of contracting an infectious disease.
2. The Organ Procurement Organization is responsible for the medical/social evaluation of each potential donor to reduce the risk of transmission of any donor illness. If a donor's social history indicates that the donor could potentially be in a "window period" for transmission of HIV, Hepatitis C, Hepatitis B or other infectious disease, you will be notified of the risk of contracting these diseases. A window period for transmission means that the donor may test negative for the disease but a review of social and/or behavioral history of the donor may indicate that he/she may have recently become infected and therefore may be infectious to others. In this situation, the transplant physician will discuss this potential risk with you.
3. A candidate who is positive for Hepatitis C virus in the blood may be offered kidneys from deceased donors who are also Hepatitis C antibody positive. The benefit of this is that waiting time is decreased significantly for patients accepting Hepatitis C positive donor kidneys. The risks of being transplanted with a Hepatitis C positive kidney include:
  - a. Worsening of liver function
  - b. Infection
  - c. Decreased survival of the transplanted kidney
4. A kidney with a high KDPI score has the following risks:
  - a. Increased risk of the kidney not functioning as well as a kidney with a lower KDPI score.
  - b. Increased risk that the kidney may be slow to function immediately after transplant

- c. The transplanted kidney may not last as long as a low KDPI kidney, even if there are no other risk factors.
- d. A small percentage of high KDPI kidneys (1-2%) may never function at all.

Under specific circumstances, a recipient may be offered two kidneys instead of one from the same donor with a high KDPI score, if the transplant team determines that one kidney may provide inadequate kidney function to the recipient. Transplantation of two kidneys in a patient at the same time is considered to give the recipient the advantage of receiving additional filtering units and therefore better kidney function. The operation is challenging and different and therefore will be offered only to patients who may benefit and can be safely transplanted with this procedure.

At the time of your evaluation, you will be asked to sign an Informed Consent for Kidney Transplant Using Kidney with a High KDPI stating whether you wish to be considered for these types of offers.

5. Kidneys Donated after Cardiac Death ("DCD") have increased risk for several things including (but not limited to) the following:
  - a. Slow or delayed initial functioning (Delayed Graft Function)
  - b. Risk of rejection
  - c. Failure of kidneys to work at all (Primary Nonfunction)
  - d. Rare instances of blood clot formation in the transplanted kidney (Graft Thrombosis) resulting in immediate failure of the kidney

Patients are encouraged to consider organ offers from High KDPI and DCD donors, because the average wait time for a kidney transplant currently exceeds five years in New Jersey. Many patients in the U.S. die while awaiting an organ transplant. Tremendous progress has been made in the area of transplanting High KDPI and DCD kidneys, and success rates are very good. The alternative for patients is to remain on dialysis, where overall health may deteriorate and quality of life may be diminished. Remember, your transplant team has carefully considered the organ offer made to you and has determined that this is an acceptable offer despite the risks outlined.



## N. Psychosocial Risk Factors

Transplant recipients vary widely in their experience with transplantation and how they cope with the many “ups and downs” that can accompany the short and long-term period following transplantation. The following are some general psychosocial risk factors that have been reported.

1. Generalized anxiety or anxiety related to a specific issue such as:
  - a. Waiting period leading up to transplant
  - b. Recovery
  - c. Uncertainty about the future
  - d. Risk of rejection and loss of the transplant kidney
  - e. Dependency on others for care and support
  - f. Financial stressors
2. Depression
  - a. Reactive to unmet expectations
  - b. Difficult post-operative course
3. Post-Traumatic Stress Disorder (PTSD)

Patients with a significant history of psychiatric illness including PTSD, anxiety and/or depression may be at increased risk for worsening of their symptoms.
4. Coping with possible side effects of immunosuppression and other medications
5. Adjusting to possible changes in such things as
  - a. Lifestyle
  - b. Family roles and responsibilities
  - c. Body image
  - d. Sexual functioning
6. Possible substance abuse or re-lapse related to stressors outlined
7. Non-compliance with medications and follow-up
8. Vocational/Work
  - a. Need for short-term disability leave
  - b. Risk of losing job or long-term disability benefits
  - c. Issues related to return to work following prolonged period of disability

An understanding of the psychosocial risk factors related to transplantation along with understanding the financial considerations outlined below will help you to prepare emotionally for a successful outcome following your surgery.

## O. Financial Considerations

Transplantation is an expensive undertaking that requires a serious commitment. It represents a partnership between you, your physicians, and the transplant team. Therefore, it is important for you to understand the terms and conditions of your current insurance and to keep apprised of any changes that may occur with your coverage. The Financial Coordinator and Transplant Social Worker will explain the financial considerations involved in transplantation and verify your health insurance coverage both initially and periodically. However, it remains your responsibility to be aware of any changes to your insurance coverage and to contact the Financial Coordinator immediately. Failure to do so may jeopardize your ability to receive a transplant.

Most patients with Chronic Kidney Disease are eligible to receive Medicare benefits through the federal ESRD Medicare Program. Medicare may cover most of the costs related to transplantation, if you are eligible; however, there are many expenses that will need to be coordinated with other insurance coverage such as private insurance, a Medi-Gap plan or Medicaid. This has been reviewed with you and your family and you have been given additional information appropriate to your circumstances if necessary.



In some situations, Medi-Gap premiums are subsidized through grants obtained by the dialysis unit. This assistance will terminate after transplantation so it is important to plan appropriately. Patients also need to understand that Medicare or other disability entitlements such as Medicaid, may be affected by transplantation. For example, Medicare benefits terminate three years after a successful transplant if there are no other qualifying disabilities.

### ***Special financial considerations if you have a living donor***

Your health insurance will be billed for the donor evaluation and the hospital expenses for the donation. The donor's insurance will not be billed. Only tests ordered by the transplant team to determine if the donor can donate to you will be covered. Any tests that are performed on the donor for the purposes of routine medical care or treatment and not ordered by the transplant team will be the responsibility of the donor and/or the donor's insurance company, and will not be billed to you or your insurance.

Health insurance generally does not pay for any personal expenses of the living donor. Donors may receive assistance to help pay for these expenses from the recipient. Donor expenses that may be covered may include travel, housing, lost wages, childcare, and food. Grants may be available for those recipient and donor pairs who financially qualify. Your transplant social worker will review your insurance coverage for living kidney donors with you and can provide you with more information on resources and assistance that may be available. Your transplant social worker will also be able to guide you on how to talk with your donor about paying for any personal expenses, if needed.

Recipients and donors should understand that it is illegal to receive monetary payment or any other items such as property, vacations, etc. (this is called valuable consideration) for agreeing to be a donor. Under the National Organ Transplant Act (NOTA), the sale or purchase of organs is a federal crime, subject to a \$50,000 fine or up to five years in prison.

Any donation-related medical problems that the donor experiences post-donation may be covered by your health insurance. You will be educated on what donor expenses your health

insurance will pay for and what your out of pocket costs may be if these expenses are incurred. Future health problems experienced by the donor that are not related to donation will not be paid for by your health insurance. Any expenses for post-donation routine follow-up care for the donor will be submitted to the donor's health insurance policy or billed to the donor directly.

### **P. Hospital Admission**

If you are receiving a kidney from a living donor, your surgery will be scheduled. Approximately two weeks prior to surgery, the donor, recipient, and family members will attend a "Pre-Surgical Meeting". At this meeting the surgical procedure for both the donor and recipient will be reviewed. The risks and benefits of receiving this living donor organ will have been reviewed with you by this time. Your medical suitability to undergo the transplant operation will be re-evaluated. A significant change in the candidate's health status may, in certain circumstances, lead to postponement or possibly cancellation of the transplant surgery.

If you receive an organ from a deceased donor you will be admitted to the hospital as directed by the transplant coordinator. You will need to bring your insurance cards, a picture ID, and your medication list with you as well as your Advanced Directive, if you have one. When you arrive, you will have necessary laboratory and medical testing done. You will be admitted by the transplant physician who will review the known risks and benefits of that donor organ with you. You will meet the surgeon and anesthesiologist at this time also.

### **Q. Patient Rights and Grievance Process**

The State of NJ Hospital Patient Bill of Rights outlines your rights as a patient at our health care facility. All patients are asked to sign an acknowledgment form stating their receipt of these rights.

In addition to the grievance procedures listed on the State of NJ Hospital Patient Bill of Rights, patients with chronic kidney disease have several other alternatives. If a grievance or complaint cannot be resolved to the patient's satisfaction through the Transplant Program Administrator and/or the Medical Center's Patient Experience Department, the patient or



family may contact the Quality Insights Renal Network 3 per their ESRD Consumer Complaint/Grievance Procedure at 1-609-490-0310.

In addition, UNOS provides a toll-free patient services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general at 1-888-894-6361.

### **R. Transplant Services Received at a Non-Medicare Certified Facility**

The Renal and Pancreas Transplant Program of RWJUH are Medicare approved facilities. However, you should know that if the transplant recipient were to receive his/her transplant at a non-Medicare approved transplant center it could affect the recipient's ability to have immunosuppressive drugs paid for under their Medicare Part B.

## **The Transplant Surgical Procedure**

### **A. Prior to Transplant**

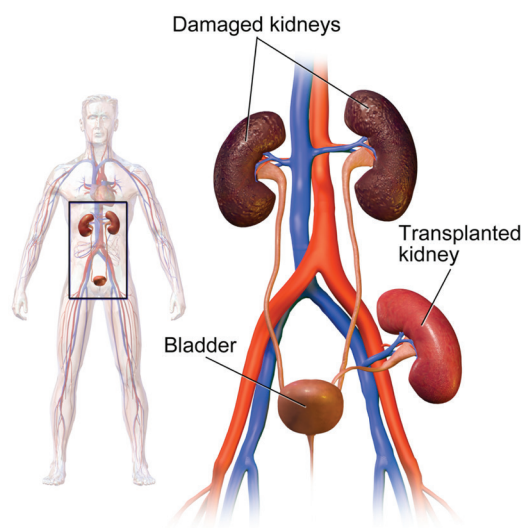
In preparation for surgery, you may expect to have blood drawn to determine whether or not dialysis treatment is necessary before your surgery. In addition, an electrocardiogram (EKG) will be done to ensure your cardiac status is stable. An intravenous line may be inserted into a large vein (near your collarbone). It will provide a way to administer medications, fluids, and possible blood products prior to, during, and after surgery. An additional IV line may be started in your arm. Antibiotics and anti-rejection medications will be administered either orally or through the IV.

### **B. The Transplant Operation**

You will meet the transplant surgeon who will discuss the technical aspects of the operation with you and will ask you to sign an informed consent. When you are taken to the operating room you will be given general anesthesia. The average length of surgery is 3 to 4 hours. A tube (catheter) will be inserted in your bladder to help pass urine and monitor urine output.

Once a compatible organ has been found, the surgeon places the kidney on one side of the recipient's front lower abdomen, using a 4-10 inch incision. The kidney placement in the abdomen allows the surgeon to more easily connect the kidney to the bladder. To ensure an adequate blood supply, the surgeon also attaches the kidney to an artery and vein that lead to the legs. In most cases, the patient's native (original) kidneys are not removed. The transplant operation typically lasts 3 to 4 hours. A tube (catheter) will be inserted in your bladder to help pass urine and monitor urine output.

After the transplant operation is completed, you will be brought to the recovery room, where you will stay until the transplant physician decides that you can be transferred to the next level of care, which is usually a direct transfer to the Transplant Floor.



### **C. The Hospital Stay**

Because your immune system will be suppressed by medications, you should have as few visitors as possible. To further prevent infection, flowers are not allowed. You will remain in the hospital until discharged by your physician (the average length of hospital stay is 3 to 5 days). Several members of the transplant team will teach you how to care for yourself following transplantation including how to organize and take your medications. You will receive an educational manual named Planning for Home that has been prepared especially for you and your family. It will help you understand the best way to take care of yourself and your new transplant.

## D. After Transplant

After you are discharged home, you will receive follow up care in the Transplant Clinic. Initially, you will be seen a few times per week. Gradually, the length of time between visits will increase depending on your particular situation. Several months after successful transplantation, you may return to your own kidney doctor (nephrologist) for monthly check ups with regular periodic monitoring at the Transplant Clinic. Some nephrologists prefer that their patients return to them even sooner and this decision will be made by you, your transplant doctor and your nephrologist. Transportation to your clinic appointments and any follow-up care that is required is your responsibility. The transplant center does not provide transportation.

## E. Medical/Surgical Risks and Complications

There is no guarantee that the transplanted organ will work immediately or even work at all. Following is a list of uncommon but known complications of kidney transplant.

1. Potential surgical complications can include, but are not limited to:
  - a. Clotting of transplanted kidney - This means that the transplanted kidney fails to work at all in the recipient due to a blood clot in the kidney. This occurs in 1 to 2 % of the cases. The recipient may then require a second surgery in an attempt to correct the problem or remove the kidney if the problem is not correctable.
  - b. Urine leakage requiring repair
  - c. Rupture of transplanted kidney
  - d. Collection of fluid around transplanted organ with or without a blockage
  - e. Bleeding requiring a transfusion and/or a re-operation to drain collected blood and stop bleeding
  - f. Wound infection
  - g. Wound separation requiring repair or wound care
  - h. Death
  - i. Unexpected complications related to the actual operation
  - j. Injury of the femoral nerve (a large nerve supplying the leg on the side of the transplant procedure), resulting in temporary or permanent leg weakness.

2. Potential medical complications can include, but are not limited to:
  - a. Acute rejection: The recipient's immune system recognizing the donor's kidney is called rejection. The majority of rejection episodes are successfully treated with medication and kidney function returns to normal
  - b. Kidney biopsy: A kidney biopsy is the best way to diagnose rejection. The risk associated with this procedure are bleeding and infection.
  - c. Infection other than wound infection
  - d. Delayed or slow transplant kidney function that may require dialysis
  - e. Medication related complications such as unexpected side-effects
  - f. Risk of heart attack, arrhythmia or stroke
3. Potential long term transplant complications can include, but are not limited to:
  - a. Chronic rejection
  - b. Complications related to long-term immunosuppression such as osteoporosis and increased risk of cancer and infection
  - c. Development of new onset diabetes

## Program Plan of Coverage

The Renal and Pancreas Transplant Program is overseen by the Program Director and consists of Board Certified Nephrologists and Board Certified Surgeons who specialize in transplantation and participate actively in the clinical activities of the Transplant Program. The Transplant Physicians cover all areas of transplant patient care including pre-transplant, in-patient services, post- transplant clinic, transplant short stay unit, transplant research and emergency room care/admissions.

The Transplant Physician Service also provides on-call coverage after hours for the program. Coverage consists of a transplant surgeon and a transplant physician available 365 days a year, 24 hours a day, and 7 days a week. All post-transplant patients will have access to routine care during normal business hours and will have access to urgent care 24 hours a day, 7 days a week.

All patients who are associated with the Transplant Program (evaluation patients, active UNOS wait list patients and post-transplant patients) will be notified in writing, by the



Program Director or his designee, of any circumstance which would impact their ability to receive a transplant or subsequent care at this center. Such circumstances may include, but are not limited to, loss of Medicare certification, notification by UNOS of an adverse action imposed upon the program, unavailability of a transplant surgeon, or a disaster situation requiring transfer of patients due to the program's temporary or permanent closing. In the event of a disaster, written notification may be delayed due to the effects of the disaster. In this event, patients are instructed to contact the UNOS Patient Services line for immediate assistance at 1-888-894-6361.

You will be given a document which represents the most current national and center-specific data obtained from the UNOS Scientific Registry for Transplant Recipients at the time of your initial evaluation and then again at the time of your transplant. As part of the consent process at the time of transplant, we will verify that you have received the most current SRTR data on national and center specific outcomes.

## **Confidentiality**

All communication between patients and RWJUH are confidential. Hospital personnel who are involved in the course of your care may review your medical record. They are required to maintain confidentiality as per law and the policy of this institution. If you do become a transplant candidate/recipient, appropriate medical information which will include your identity, will be sent to the NJ Organ and Tissue Sharing Network and to UNOS and may be sent to other places involved in the transplant process as permitted by law.

## **Accessing Updated Information**

Technology in the field of transplantation is always improving as science evolves. New medications are developed and advanced techniques are implemented. As such, it is important that you remain informed of the most up to date information as it relates to your pending transplant. Please be sure to visit our website at [www.rwjuh.edu](http://www.rwjuh.edu) access information. The Transplant Candidate Education Program as well as National and Center specific outcomes will be updated regularly. You may also contact your transplant coordinator at any time to request a mailed copy.

## **Recipient Outcome Information**

In general, outcomes for transplant recipients are excellent. The Scientific Registry of Transplant Recipients (SRTR) publishes updated reports every six (6) months on activities at each transplant center and organ procurement organization in the United States. This can be accessed by visiting their website at [www.srtr.org](http://www.srtr.org).

