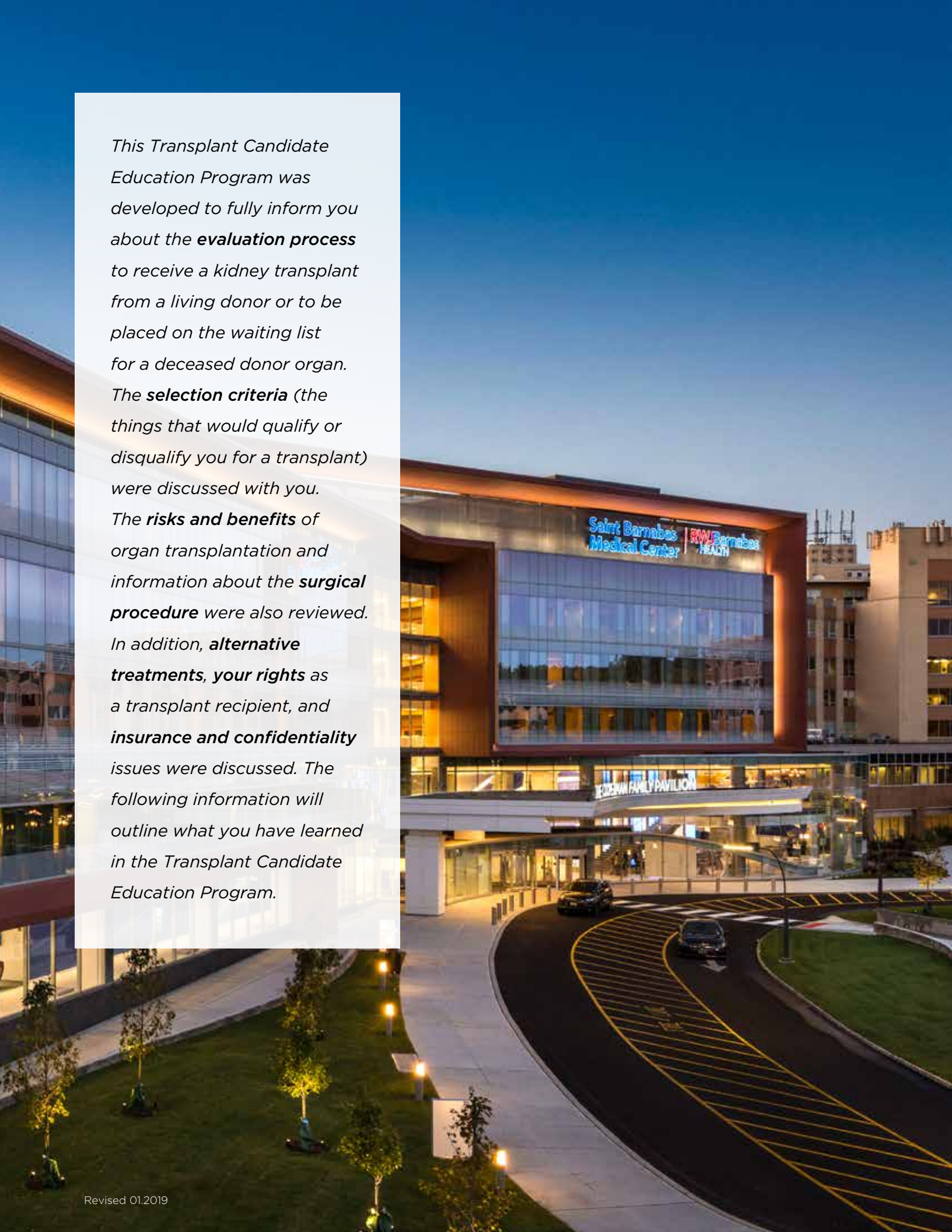
Pediatric Kidney Transplant Candidate Education Program

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

Barnabas Health Medical Group
Children's Kidney Center

RWJBarnabas HEALTH



This 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
         (A) *Living Donor Kidney Exchange Program:* for recipients with willing, medically acceptable living donors who are incompatible by blood type or crossmatch, recipient/donor pairs are entered into a registry for an exchange match.
         (B) *Program for Incompatible Transplants:* for recipients with willing, medically acceptable living donors who have incompatible blood type or crossmatch compatibility issues. Recipients receive medical therapies before and after transplant to significantly increase the likelihood for a successful transplant outcome.

C. Recipient Benefits

According to the most recent United Network for Organ Sharing ("UNOS") data:

1. On average, children who receive a kidney transplant have significantly increased life expectancy compared to children who are maintained on dialysis while waiting for a kidney.
2. On average, diabetic transplant recipients live longer than diabetic patients who are maintained on dialysis.
3. Most transplant recipients report an enhanced quality of life through improved health and energy.
4. 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** (For Spanish version, the website is **www.trasplantesyvida.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.transplantkidney.org – RWJBarnabas Health Renal and Pancreas Transplant Division.

www.rwjbh.org/ldi – RWJBarnabas Health Living Donor Institute. Information about living kidney donation and on-line and printable donor referral forms.

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.

B. Education Session

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

1. Selection criteria (conditions or factors that qualify you or may disqualify you from receiving a transplant)
2. Testing requirements needed for medical clearance
3. Tissue-typing and cross matching (checking to see if your tissue/blood matches the donor)
4. How the wait list works, including multiple wait listing and transfer of wait time
5. Living and deceased donor organs: types and issues specific to each type
6. You and your family's responsibilities in preparation for and after you receive a kidney transplant
7. What happens when an organ becomes available
8. Overview of the transplant surgery
9. The general hospital experience with transplant
10. Common immunosuppressant medications and their side effects
11. Post-Transplant Care — visits to the transplant clinic
12. Possible transplant complications, such as rejection and infection
13. Financial considerations
14. 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. Discussion of immunization history and needs to be communicated to pediatrician
    c. Education/discussion about the option of living kidney donation
    d. Discussion of learning needs in preparation for understanding medication administration after transplant
    e. A review of compliance with your current medical regimen (e.g. dialysis, medication)
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, school-related issues 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 the psychosocial risks including possible emotional, financial, and physical stressors that receiving a transplant may pose to you and your family
    e. Education/discussion about the option of living kidney donation
    f. 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
    g. For adolescents, a 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
    b. Education and discussion of possible dietary needs after transplant.

D. Overview of Requirements for Medical Clearance

1. Basic Testing (within the last 12 months)
   a. Medical History and Physical – from referring nephrologist
   b. Chest X Ray
   c. Electrocardiogram (EKG)
   d. Complete blood work results from your dialysis unit or MD office
   e. Serologies: Hepatitis B and C, and HIV, EBV, CMV, Rubeola, Varicella, RPR
   f. Social Work Assessment from dialysis unit – if you are on dialysis
   g. Medical Evidence Report (MER) from your dialysis unit - if you are on dialysis
2. Cancer Screening
   a. PAP smear for sexually active females
3. Cardiac Testing: Echocardiogram and cardiology consult **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 cardiac failure or cardiac surgery
4. 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 pediatric patient with Chronic Kidney Disease (CKD) with a GFR ≤15 mL/min, either on dialysis or approaching dialysis, may be considered for kidney transplantation. Candidates must have successfully completed the evaluation process including medical and psychosocial clearance. The pediatric transplant team then makes a decision regarding the patient's suitability for transplant based on the established selection criteria and the patient's current medical and psychosocial status as well as 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 include:

Medical/Surgical

- Serious heart disease, ejection fraction (EF) less than or equal to 30%
- Chronic infections (unresolved)
- Advanced Pulmonary Disease
- Advanced Liver Disease (i.e. Cirrhosis of the liver)
- Metastatic Cancer
- Active vasculitis
- Active infection (i.e. peritonitis, abscess)

Psychosocial

- Chronic proven non-compliance with medication and/or prescribed treatment(s)
- *Active substance abuse
- Absence of funding for transplant procedure, hospital charges and/or medications
- *Untreated psychiatric condition(s), including suicide risk
- *Severe psychiatric illness, uncontrolled with medication
- Lack of citizenship or residency status may preclude listing for deceased donor transplant
- Poor social support including absence of confirmed caregiver during the immediate post-transplant period
- Multiple medical conditions and/ or psychosocial risk factors which, in combination would make transplantation too high risk for the patient.

* Psychiatric consultation/clearance may be indicated

F. Yearly Updating of Tests

Your transplant coordinator will inform you and your family 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. 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. Crossmatching 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. 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 and sent directly to The Sharing Network. Your transplant coordinator will teach you exactly how to fulfill this very important responsibility. If a current blood tube is not at The Sharing Network at the time a deceased donor kidney is identified for you, you may lose the opportunity to receive that kidney.

I. Activation on the Waiting List

To become active, you must complete all of the evaluations and diagnostic tests required and be considered medically and psychosocially eligible. You will be sent an official letter from your transplant coordinator informing you of the date that you are made active on the transplant waiting list. In addition, your nephrologist and your dialysis unit (if applicable) will be notified.

J. How the Wait List Works

When a deceased donor organ becomes available, you must be blood group compatible. A list of potential blood group compatible recipients is generated based on a point system. The points are allocated based upon time waiting, quality of match, high recipient PRA (Panel Reactive-Antibody) and pediatric recipient status. If you are on this list, you or your family 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 The Sharing Network. You or your family 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.

As soon as a center accepts you as a transplant candidate, your "waiting time" begins.

Under Organ Procurement and Transplantation Network (OPTN) policy, you can list at more than one transplant center (multiple-list) as long as you don't choose two transplant centers in the same local area. As with any transplant listing, you must be evaluated and accepted by a transplant center. You or your family 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 or your family would need to maintain current lab results and contact information for each transplant program where you're listed.

The longest amount of time you have waited at any center is called your 'primary waiting time'. If you list at multiple centers, your waiting time at each center will start from the date that center listed you. OPTN policy allows you to transfer your primary waiting time to another center where you are listed, or switch time waited at different programs. You are not allowed to add-up or split your total waiting time among multiple centers. Any request to transfer or switch waiting time must be approved by the transplant center(s) involved, and may require a written request from the patient.

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 us to express their interest in donating to you. Once it is determined that you are a candidate for transplant, your donor will be directed to our Living Donor Institute for education and to begin the evaluation process.

- If you do not have a willing living donor but are interested in the option of living donation, the Living Donor Institute 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 Living Donor Institute 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 Institute 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 Saint Barnabas Medical 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 through the Living Donor Institute.

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

   The two types of Altruistic Living Donors are directed altruistic donors and non-directed altruistic donors.

- The 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.
- The 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

   In this program, 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 who 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.

6. Program for Incompatible Transplants

   Many patients have living kidney donors who are incompatible by blood type or crossmatch. These donors may be otherwise able and willing to donate. Depending on the type and degree of incompatibility, this program offers some potential recipients the option to receive a living donor kidney from their incompatible donor.

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
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

N. Psychosocial Risk Factors

Children receiving a kidney transplant and their parents 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 ("Is it going to hurt?")
    c. Uncertainty about the future ("Will I be able to have children?" "Can I play sports?")
    d. Risk of rejection and loss of the transplant kidney
    e. Financial stressors (worries about making ends meet; out-of-pocket expenses; access to public program; insurance issues etc.)
2. Depression
    a. Reactive to unmet expectations
    b. Difficult post-operative course
3. Post-Traumatic Stress Disorder (PTSD) or delayed shock following diagnosis

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. Body image (i.e. acne for teenagers, surgical scar)
    c. Sexual functioning
6. Possible substance abuse or re-lapse related to stressors outlined
7. Non-compliance with medications and follow-up
8. School concerns
    a. Educational accommodations for primary and secondary students (i.e. home instruction)
    b. Missed class time/assignments or need for temporary semester withdrawal for college students
9. Work issues for parent(s)/caretaker
    a. Fear of losing job
    a. Issues related to Family Medical Leave and return to work after prolonged period of caretaking

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 let us know 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 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 planned to coordinate with school and work schedules. One week prior to surgery, the donor, recipient, and family members will attend a "Family 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 pediatric nephrologist. You or your family will need to bring your insurance cards and your medication list with you. 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. If there is a research protocol for which you are being considered, this will be discussed with you and your family also at this time. If you and your parents/guardian choose to participate, the transplant physician will take informed consent for the research protocol at this time.

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 Department Administrator and/or the Medical Center's Patient Satisfaction 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 Division of RWJBarnabas Health are Medicare approved facilities. However, you should know that if the transplant recipient were to receive their transplant at a non-Medicare approved transplant center, the recipient's immunosuppressive drugs might not be paid for under their Medicare Part B.

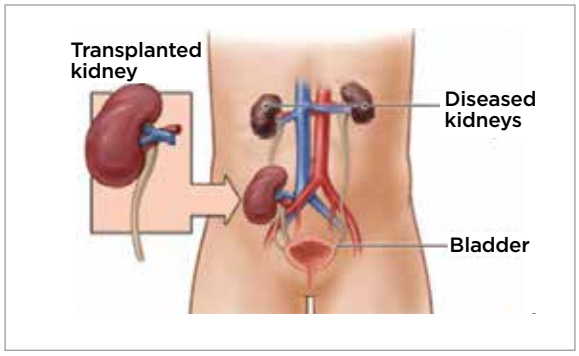
The Transplant Surgical Procedure

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 and/or your parents/ guardian to sign an informed consent.



Once a compatible organ has been found, the surgeon generally places the kidney on the right, lower side of the child's 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. In smaller children, the kidney is placed through an incision in the middle of the child's abdomen. 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 into the child's bladder to help pass urine and monitor urine output.

After the transplant operation is completed, you will be brought to the Pediatric Intensive Care Unit, where you will stay until the transplant physician decides that you can be transferred to the next level of care, which is usually the Pediatric Step-Down Unit.

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 5 to 7 days). Before you are discharged, all the tubes, IVs and catheters placed during surgery will be removed. The Pediatric Nephrology Nurse will teach you how to care for yourself following transplantation including how to organize and take your medications, how to monitor your blood pressure if needed, about follow-up appointments, signs of rejection and other warning signs to watch for at home. 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 Children's Kidney Center. Initially, you will be seen several times per week. Gradually, the length of time between visits will decrease depending on your particular situation. Several months after successful transplantation, you may return to your own kidney doctor (nephrologist) for monthly check ups with only periodic monitoring at the Children's Kidney Center. Some nephrologists prefer that their patients return to them even sooner and this decision will be made by you, your parents/ guardian, your transplant doctor and your nephrologist. Transportation to your clinic appointments and any follow-up care that is required is your responsibility. The Children's Kidney 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. Respiratory problems requiring the need for ventilator support
   b. Acute rejection:
      (i) 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
      (ii) Kidney biopsy: A kidney biopsy is the best way to diagnose rejection. The risk associated with this procedure is 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
3. Potential long term transplant complications can include, but are not limited to:
   d. Chronic rejection
   e. Complications related to long-term immunosuppression such as osteoporosis and increased risk of cancer and infection
   f. Development of new onset diabetes

Program Plan of Coverage

The Children's Kidney Center is covered by two Board Certified Pediatric Nephrologists as well as Board Certified Surgeons who specialize in pediatric transplantation and participate actively in the clinical activities of the Program. Physicians are selected and overseen by the Chief of the Transplant Division, Chair of the Department of Pediatrics and Director of Transplant Surgery based on qualifications, experience, and the needs of the Program. The Pediatric Nephrologists and Transplant Surgeons cover all areas of transplant patient care including pre-transplant, in-patient services, post- transplant clinic, transplant research, and emergency room care/admissions.

The Pediatric Nephrologists and Transplant Surgeons also provide on-call coverage after hours for the Program. Coverage consists of a Transplant Surgeon and a Pediatric Nephrologist 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. Additionally, The Chief of Transplant is available to provide back-up coverage and consultation to both the Children's Kidney Center and to Transplant Coordinators who are on-call for organ allocation issues.

All transplant patients who are associated with the Children's Kidney Center (evaluation patients, active UNOS wait list patients and post-transplant patients) will be notified in writing, by the Chief of the Transplant division 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.

Confidentiality

All communication between patients and The Children's Kidney Center 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. In addition, your parents will be provided with information regarding your care and treatment.

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.transplantkidney.org** to 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**. This data can also be accessed by visiting our own Barnabas Health Transplant Division website at **www.transplantkidney.org**.

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.

Barnabas Health Medical Group
Children's Kidney Center

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