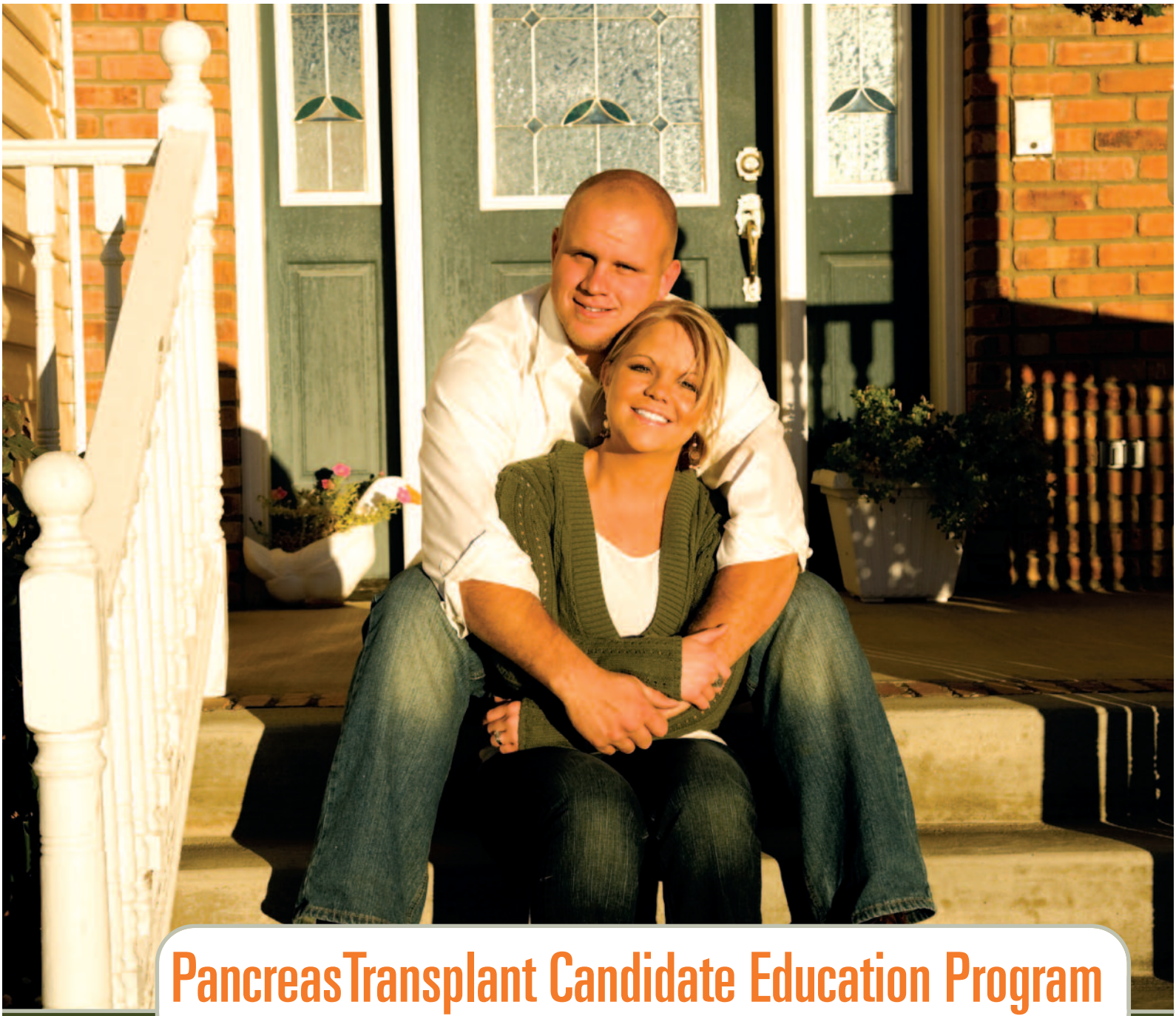

Pancreas Transplant Candidate Education Program

– Confirmation of Education

The Pancreas Transplant Candidate Education Program is an additional educational tool that builds upon what you learned during the kidney transplant education program and evaluation. It was developed to fully inform you about the evaluation process to be placed on the waiting list for a deceased donor pancreas. The risks and benefits of pancreas transplantation and information about the surgical procedure were reviewed. In addition, the alternative treatments available for diabetes, your rights as a transplant recipient, and insurance and confidentiality issues were discussed. The following information will outline what you have learned in the Pancreas Transplant Candidate Education Program.

1.888.409.4707 www.transplantkidney.org

Barnabas Health
Renal and Pancreas Transplant Division

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 Type I Diabetes or an inability to make insulin have several options:

1. Medication management with insulin
2. Pancreas Transplantation from a deceased donor as either:
   a. Simultaneous Pancreas Kidney Transplant ("SPK") which means that recipient receives both organs from a deceased donor at the same time.
   b. Pancreas after Kidney ("PAK") which means that the recipient receives a donor kidney and then receives a deceased donor pancreas at least 2 months later. Your may receive your kidney transplant in several ways:
      (i)Deceased donor kidney
      (ii) Living donor kidney
         (A) Compatible Donor
            - Related: blood or genetically related
            - Unrelated: emotional connection (e.g., spouse, in-law, friend)
         (B) 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.
            - Program for Incompatible Transplants: for recipients with willing 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") 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. On average, patients who receive a kidney transplant and a pancreas transplant almost double their life expectancy compared to those who are maintained on dialysis. However, this benefit does vary between individual patients.
3. Many recipients of a pancreas transplant (in addition to a kidney transplant) benefit from a slowing of the damage caused by Type I Diabetes mellitus to body organs such as eyes, nerves, and blood vessels of the legs and heart. In some cases patients have an improvement in the damage done to these organs.
4. Most pancreas transplant recipients report an improved quality of life through liberalized diet and freedom from daily insulin injections.
5. Most pancreas transplant recipients report an enhanced quality of life through improved health and energy.
6. 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 and/or pancreas transplantation:

A. 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.

B. 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.

C. 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).

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

E. www.kidneyfund.org - American Kidney Fund (AKF).

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

G. www.kidney.org - National Kidney Foundation.

H. www.transplantkidney.org - Barnabas Health Renal and Pancreas Transplant.

I. www.mytransplantlife.com/ - A resource website for transplant candidates and living donors sponsored by Genentech.

The Evaluation Process

A. Eligibility

The evaluation process determines if you are medically eligible to receive a pancreas transplant and 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 your health status is optimal and that you would be able to be safely transplanted. If a new health problem is found during the evaluation, you may be referred back to your nephrologist, primary care physician, or the appropriate medical specialist. If a serious health problem is found, it is possible that you may be ineligible to receive a pancreas transplant.

The Transplant Team makes a decision regarding your suitability for transplant based on your current medical and psychosocial status as well as the results of required testing. This decision will be discussed in detail with you.

B. Overview of Requirements for Medical Clearance

For SPK transplant, the patient must first undergo evaluation for kidney transplantation. For PAK transplant, the patient must have already undergone kidney transplantation. The pancreas evaluation then includes:

1. For SPK, medical history and physical examination with pancreas transplant surgeon
2. For PAK, medical clearance from transplant physician then medical history and physical examination with pancreas transplant surgeon as well as re-evaluation with the transplant coordinator, social worker and dietician
3. Ophthalmology evaluation (if indicated)
4. Laboratory testing:
   a. C-Peptide
   b. Repeat 24 hour urine testing for creatinine clearance, for patients undergoing PAK
   c. Hemoglobin A1C

C. Recipient Selection Criteria

The following selection criteria guides the transplant team in their decision making.

1. SPK Recipient Selection Criteria
   a. Patient has Type I diabetes
   b. Patient is age 55 years or less
   c. Patient has Chronic Kidney Disease with a creatinine clearance of 25 or less.
   d. Patient has had minimal abdominal surgery (Acceptable prior operations include: peritoneal dialysis catheter, appendix removal, and uncomplicated gallbladder removal)
   e. Patient has normal or acceptable cardiac stress test
   f. If patient is 45 years old or greater with a history of diabetes for 20 years or greater, patient has undergone coronary angiography or has considered such option and elected not to undergo the procedure for reasons that are acceptable to the transplant team
   g. Patient is highly motivated and understands what may be involved during post-operative recovery (e.g., the possibility for further surgical procedures, re-hospitalization, close follow-up in clinic)
2. PAK Recipient Selection Criteria
   a. Patient has Type I diabetes

b. Patient is age 55 years or less.
c. Patient has stable kidney transplant function and is on a regular routine of transplant medications with a blood level creatinine of less then 2 mg/dL or creatinine clearance urine test of greater than 40
d. Patient has difficult-to-control diabetes and/or the patient lacks symptoms of low blood sugar
e. Patient has had minimal abdominal surgery (acceptable prior operations include: peritoneal dialysis catheter, appendix removal, and uncomplicated gallbladder removal)
f. Patient has normal or acceptable cardiac stress test
g. If patient is 45 years old or greater with a history of diabetes for 20 years or greater, patient has undergone coronary angiography or has considered such option and elected not to undergo the procedure for reasons that are acceptable to the transplant team
h. Patient is highly motivated and understand what may be involved during post-operative recovery (e.g., the possibility for further operative procedures, re-hospitalization, close follow-up in clinic)

D. High Risk Patient Criteria

Patients with the following high risk factors may be considered for evaluation on a case by case basis:

1. Type II diabetics (SPK only)
2. Hepatitis C antibody positive patients. [All patients must have the following completed:
   a. Laboratory Testing
      (i)Hepatitis C PCR quantitation (viral load)
      (ii) Liver function tests
      (iii) Liver biopsy

E. Relative Contraindications to Pancreas Transplantation:

1. Medical issues that would disqualify a recipient from pancreas transplantation are the same as for kidney transplantation with the following additions:
   a. Body Mass Index of 30 or greater
   b. HIV positive
   c. Hepatitis B surface antigen positive
2. Additionally, pancreas transplantation may be contraindicated in the presence of advanced, irreversible damage to body organs effected by diabetes since the benefit of transplantation would be minimal. Examples include blindness, loss of limbs due to peripheral vascular disease, severe gastroparesis, and advanced autonomic and sensory neuropathy.

F. Financial Considerations

Medicare does cover SPK and PAK transplantation in the same way as kidney transplantation. Assessment and screening by the financial coordinator and the transplant social worker are necessary to ensure adequate medical coverage as well as for medications and follow-up care required

G. Re-transplant

Patients requiring re-transplant will be discussed on a case-by-case basis

H. Education Sessions – Initial Kidney Transplant Evaluation

The following information topics were reviewed during your initial kidney transplant evaluation:

1. Testing requirements needed for medical clearance
2. Tissue-typing and cross matching
3. How the wait list works including multiple wait listing and transfer of wait time
4. Living and deceased donor organs: types and issues specific to each type
5. What happens when an organ becomes available
6. Overview of the transplant surgery
7. The general hospital experience
8. Common immunosuppressant medications and their side effects
9. Post Transplant Care - visits to the transplant clinic
10. Possible transplant complications: (e.g. rejection, infection)
11. Financial considerations
12. Healthy lifestyle following transplantation

I. Education Session – Pancreas Transplant Evaluation

The following information was reviewed during your pancreas transplant evaluation:

1. The basic function of the pancreas

a. At birth, the pancreas lies below the stomach at the beginning of the small intestines. It performs many functions. The pancreas produces digestive juices and it also produces insulin. Insulin is vital to the body in order for it to use sugar.
b. The digestive juices break down most of the food we eat into glucose, which is a simple sugar. Glucose is the body's main source of fuel. After digestion, the glucose passes into the bloodstream where it is used as fuel for growth and energy. This process can not take place without insulin.
c. When you eat, your pancreas is automatically supposed to send out the correct amount of insulin to move glucose from your blood into your cells. However, in people with Type 1 diabetes the pancreas does not perform this correctly. As a result, glucose can not get into the cells so it builds up in the blood, overflows into the urine, and passes out of the body, leaving the cells starving for food.
d. People with diabetes have to inject themselves with the insulin that would normally be produced by their pancreas to make sure their cells get the energy they need. People with diabetes must also control their diets, change their activities and test their blood sugar according to their doctor's advice.

2. What SPK Transplant Will Do

Your SPK transplant will fix two problems at the same time. The new kidney filters the poisons out of your body that your old kidneys were unable to do, and your new pancreas will begin to produce insulin. A successful SPK transplant frees you from daily insulin shots and dialysis. Many patients report an improvement in their quality of life.

3. What Your PAK Transplant Will Do

Your kidney transplant will continue to function as it did before your new pancreas transplant. The kidney will continue to filter the poisons out of your body. Your new pancreas will begin to make insulin and will free you from daily insulin shots. Many patients report an improvement in their quality of life.

4. Location of your transplanted kidney and pancreas:

a. If you have an SPK, the old pancreas is left in place and the new pancreas is placed in the right lower quadrant of the abdomen. The kidney is placed on the other side (the left-hand side).
b. If you have an SPK, the surgeon uses a single midline incision to place the organs in the pelvic area.
c. If you have a PAK, the location of the pancreas may vary depending on where your kidney transplant was placed. However, the locations of either will be on right and left lower quadrants of your abdomen. The surgeon will usually place the pancreas in the right lower abdomen if your kidney transplant was placed in the left lower abdomen.

5. Pancreatic drainage

a. The pancreas is important in making insulin but it also has a role in digestion. Your pancreas makes enzymes that help you digest food. Your new pancreas will be connected so that these enzymes drain into your bowel.
b. Occasionally the pancreas is connected to your bladder instead of bowel. This is unusual, and the surgeon will discuss this with you if this becomes necessary. At Saint Barnabas Medical Center bladder drainage of the pancreas is not performed routinely.

6. Glucose Monitoring

a. Just as your transplanted kidney should begin to function right away, your new pancreas should also begin to produce insulin right away, and your glucose levels should be within normal limits. However, you may need to take insulin injections for a short time after your transplant surgery until your pancreas gains full function.
b. To monitor the function of your new pancreas you will probably be required to check your blood sugar at least once a day after discharge. While in the hospital the nurses will be checking it more frequently.

7. Medications

a. Your medication will be the same as a kidney-only transplant. However your dosage may be higher because of the higher risk of rejection. These higher doses may increase your risk of developing an infection.

b. You must remember to take only the medication that is prescribed to you by your physician. All of the rules are the same as for the kidney-only transplant patients. You must take your medication at the same time every day. Do not skip any doses.

8. Rejection

a. Pancreas transplant patients can have rejection in the kidney or pancreas separately or in both at the same time. Rejection is monitored by checking the function of the kidney through blood tests, and checking the pancreas by monitoring blood amylase, lipase and glucose levels. A kidney or pancreas biopsy may be performed to make the diagnosis.

b. As a pancreas transplant recipient, you may be at greater risk for early, reversible rejection than a person with a kidney-only transplant. Treatment for rejection in one organ usually prevents or treats rejection of the other as well.

c. Pancreas and Kidney transplants treat your pre-existing diseases; therefore, if either your kidney or pancreas fail, you can return to your previous treatments, and you may be able to have another transplant.

9. Diet and Nutrition

You will now be able to be more relaxed about your diet and eat some treats once in a while; however, you will need to follow a low-fat, low-sugar diet. Healthy eating is important for your well-being and important in preventing diseases so follow your dietitian's instructions very carefully.

10. Foot Care

Even though your new pancreas is treating your diabetes, it has been shown that you may still have risks for foot complications including infection. You will need to take the following steps to care for your feet:

a. Wash your feet daily, making sure to dry them thoroughly.

b. Inspect your feet daily for cuts, scratches, blisters, ingrown toenails, puncture wounds, or warts. Call your physician if you have any of these.

c. Call your physician immediately if you have signs of infection, burning, tingling or numbness in your feet.

d. Do not try to remove corns, calluses, or ingrown toenails yourself. Contact your physician.

e. Do not walk barefoot or in high-heeled shoes. Make sure your shoes are comfortable and well fitted.

f. Wear cotton socks to absorb moisture and be sure to change them everyday.

J. Evaluations

Candidates for pancreas transplantation will be evaluated by the transplant team, including nurse coordinator, social worker, transplant physician, and transplant surgeon. The evaluations will include the following:

1. Nursing Assessment, including a review of required laboratory and diagnostic testing required
2. Transplant Surgeon and Transplant Nephrologist evaluations
   a. History and physical to determine candidacy for pancreas transplant
   b. Education/discussion including risks and benefits of transplantation
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 diabetes, dialysis treatments, medications, dietary restrictions, bloodwork and laboratory testing, etc).
   d. A discussion of your reasons for wanting to become a pancreas transplant recipient
   e. A discussion of the possible psycho-social risks including possible emotional, financial, and physical stressors that receiving a transplant may pose to you and your family
   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. 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. Dietary Assessment
   You may see the transplant dietician for assessment and counseling related to dietary intake pre and post transplant and related issues. If for some reason you have not seen the transplant dietician, ask the transplant coordinator for a referral.

K. Yearly Updating of Tests

The pancreas transplant candidate is re-evaluated on a yearly basis by the transplant surgeon or the transplant physician. All testing is updated at this time as requested by the evaluating physician. 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.

L. 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 pancreas is identified for you, you may lose the opportunity to receive that pancreas.

M. 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 that you are now active on the pancreas transplant waiting list. In addition, your nephrologist and your dialysis unit (if applicable) will be notified.

N. The Waiting List

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 will receive a phone call from a transplant coordinator. To be considered for SPK or PAK offer you must be medically stable with no active infections and have your monthly blood specimen at The Sharing Network. You will receive detailed information and instructions from the transplant coordinator. Every available deceased donor organ generates a different list of potential recipients and is based on the donor's blood group. Therefore, there is no way to tell your "position on the list" until a particular organ becomes available, however, your coordinator is able to tell you the amount of wait time you have accumulated.

As soon as Saint Barnabas Medical 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 do not 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 should also check with your insurance provider to see if there 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 list.

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.

O. Donors

1. Donor organs are obtained from individuals after their death whose next of kin has given permission to have their organs donated.
2. 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 donors whose organs were donated after cardiac death. 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.

P. 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 a kidney and or a pancreas 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 donors. The risks of being transplanted with a Hepatitis C positive organ include:
   a. Worsening of liver function
   b. Infection
   c. Decreased survival of the transplanted organs

Q. Hospital Admission

When an appropriate organ becomes available, you will be instructed by the transplant coordinator to go to and be admitted to Saint Barnabas Medical Center. You will need to bring your insurance cards 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.

R. Patient Rights and Grievance Process

The New Jersey State - Ambulatory Care 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 New Jersey State –Ambulatory Care 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 Trans-Atlantic Renal Council per their ESRD Consumer Complaint/Grievance Procedure at 1-888-877-8400. 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.

S. 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.

T. Transplant Services Received at a Non-Medicare Certified Facility

Saint Barnabas Medical Center is a Medicare-approved facility. 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 will be admitted to the Transplant Floor and assessed by one of the RNs on the unit. You should also expect to have blood drawn to determine whether or not dialysis treatment is necessary before your surgery. For PAK surgery dialysis is not necessary. For both SPK and PAK surgeries, a cardiogram (EKG) will be done to ensure your cardiac status is stable and a chest x-ray will be done to assess your pulmonary status. An intravenous line usually will be inserted into your arm when you arrive, then a central intravenous line will be inserted into a large vein (usually near your collarbone) in the OR holding area prior to surgery. It will provide a way to administer medications, fluids, and possible blood products prior to, during, and after surgery. Antibiotics and anti-rejection medications will be administered initially through the IV and then switched to oral once you are tolerating a diet.

B. The Transplant Operation

For both SPK and PAK surgeries, you will meet the transplant surgeon and transplant nephrologist 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 5 to 6 hours. A tube (catheter) will be inserted in your bladder to help pass urine and monitor urine output. This catheter will remain in for several days. During the operation, a nasogastric tube is inserted through your nose and into your stomach to drain the stomach contents. This prevents vomiting after an operation which is common in diabetic patients. The nasogastric tube remains in place for several days until the surgeon feels it is safe to be removed. After the tube is removed, you will be started on a liquid diet and advanced to a solid diet as bowel function returns. 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 the Intensive Care Unit (ICU). From there, you will be transferred to the Transplant Floor.

C. The Hospital Stay

The average length of hospital stay is 10 to 14 days. 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 Inpatient Transplant Practitioner will teach you how to care for yourself following transplantation and the Transplant Pharmacist will teach you 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. During your hospital stay, your blood sugar will be monitored at regular intervals.

D. After Transplant

After you are discharged home, you will receive follow up care in the Transplant Clinic. Initially, you will be seen several 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 only 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. In addition, there is no guarantee you will have normal blood glucose levels or be free from insulin injections or oral medications to control your blood glucose following pancreas transplantation. Following is a list of uncommon but known complications of pancreas transplant.

1. Potential surgical complications of a pancreas transplant can include, but are not limited to:
   a. Clotting of transplanted pancreas. This means that the transplanted pancreas fails to work due to a blood clot and requires removal. This happens more frequently in a pancreas transplant than a kidney transplant and occurs in 5-10 % of the cases. The recipient may then require a second surgery in an attempt to correct the problem or remove the pancreas if the problem is not correctable.
   b. Leakage where the pancreas is connected to the bowel or bladder. This can require another operation to repair the leak. In some cases this can cause severe infection.
   c. Bleeding requiring a transfusion and/or a re-operation to drain collected blood and stop bleeding
   d. Wound Infection
   e. Wound separation requiring repair or wound care
   f. Abdominal abscess requiring surgical drainage

g. Infection or inflammation around the transplanted pancreas
h. Death
i. Unexpected complications related to the actual operation

2. Potential medical complications of pancreas transplantation can include, but are not limited to:
   a. Acute rejection: The recipient's immune system recognizing the donor's pancreas is called rejection. The majority of rejection episodes are successfully treated with medication and pancreas function returns to normal. Patient may require insulin during this period.
   b. Pancreas biopsy: A pancreas 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 function that may require continuation of insulin
   e. Potential for deterioration of your kidney transplant function following a PAK
   f. Medication related complications such as unexpected side-effects
   g. Risk of heart attack, arrhythmia or stroke
3. Potential long term transplant complications can include, but are not limited to:
   a. Chronic rejection
   b. Type II Diabetes requiring oral medication therapy
   c. Complications related to long-term immunosuppression such as osteoporosis and increased risk of cancer and infection
   d. Development of new onset diabetes

F. 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 issues and risks discussed earlier will help you to prepare emotionally for a successful outcome following your surgery.

Confidentiality

All communication between patients and Barnabas Health are confidential. Health Care System 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 Health Care System. If you do become a transplant candidate/recipient, appropriate medical information which will include your identity, will be sent to The Sharing Network and 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 keep abreast 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 Pancreas 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.

1.888.409.4707 www.transplantkidney.org

Barnabas Health
Renal and Pancreas Transplant Division