

Transplant 101: A Guide to Living Donor Transplantation

What is Transplant 101?

Transplant 101 is a resource guide that has been developed by the National Kidney Foundation of Georgia's Living Donor Program to answer questions about and improve access to living donor kidney transplantation.

In addition to answering commonly asked questions about living donation and kidney transplantation, Transplant 101 provides a list of community resources available to Georgia kidney patients, living donors and families.

Why transplantation?

A kidney transplant is an operation in which a person whose own kidneys have failed receives a new kidney from either a cadaver donor or a living donor. While there are drawbacks to getting a transplant, such as the expensive anti-rejection medications and the side effects they cause, most patients agree that a successful kidney transplant provides them with greater freedom, increased energy and a less restricted diet.

How does a patient become a candidate for transplantation?

The patient's kidney doctor must make the referral to a transplant center. The medical team at the transplant center will then evaluate the patient to see if he or she would make a good candidate for transplantation. Some of the things the team will evaluate include the patient's past and present medical condition, his or her history of complying with past medical instructions, and the emotional support available from the patient's family and friends.

Most transplant centers will also require patients to have a financial plan to ensure that the patient has enough money to pay for his or her medications post-transplant. If the patient has trouble meeting the financial requirements, the Georgia Transplant Foundation can help with fundraising and can provide other financial assistance.

If the medical team approves the patient for transplantation, the patient is then placed on the transplant waiting list that is administered by the United Network for Organ Sharing (UNOS). Once a patient is listed, the transplant can happen immediately or the wait for a compatible kidney can be indefinite. If the patient has a relative, a spouse or a friend who is willing and able to donate a kidney, the transplant can happen much more quickly.

How does UNOS match cadaver organs to patients waiting for a transplant?

When a patient is added to the transplant waiting list, his or her medical profile is entered into the UNOS computer database where it becomes part of a "pool" of patient names. Every time an organ becomes available, all patients in the pool are compared to the donor. The computer then generates a list of patients who match the donor organ with priority given to patients who identically match the organ.

Criteria for matches include biologic compatibility between the donor and the recipient (such as blood type and genetic makeup) and time spent on the waiting list. If there is no identical match, the donated organs are distributed locally first, then are offered regionally, then nationally.

Why is the waiting list for a cadaver kidney so long?

There are a number of reasons why the wait for a cadaver kidney can last indefinitely. One reason is that the number of people in need of a kidney transplant is increasing every day. For example, in the year 2001, there were approximately 1000 people in Georgia who were waiting on the cadaver kidney list. By 2010, it is projected that approximately 3000 people in Georgia will be waiting for a cadaver kidney.

While the list of patients is growing, the number of people who are willing to donate their loved one's organs is remaining constant. The myths and misconceptions that surround organ donation are difficult to dispel – many people think donation is against their religion or that it will cost them something or that it will delay the funeral or prevent an open casket funeral, when the reality is that none of this is true.

What is living donation?

Living kidney donation is the act of a living person donating a kidney to another person for transplantation.

Are there advantages to getting a kidney transplanted from a living donor?

Yes, there are several advantages to having a living kidney donor. These advantages include better outcomes, a shorter waiting time, a shorter time spent on dialysis, and the ability to schedule the transplant for a time when the patient will be at his or her healthiest.

Who can be a living donor?

In the past, recipients could only get a living donor kidney from a blood relative. This is no longer necessary because anti-rejection medications and compatibility tests are much better than they used to be. Today most anyone who qualifies medically, is willing and has a compatible blood and tissue type with the recipient can consider being a living donor.

Can a person live with one kidney?

Yes. After donating a kidney a person can live a long, healthy life with one healthy kidney. The remaining kidney simply grows bigger so that it can take over the work for both kidneys.

How are living donors selected?

Each Transplant Center has selective criteria based on age, medical and psychological evaluations, family history of hereditary diseases and blood and tissue compatibility. Generally a donor must be at least 18 years of age; the maximum age is usually 60 but this does vary by transplant center and often depends on the particular situation.

The medical evaluation will include a complete history and physical screening for kidney, heart, lung, liver, or circulatory problems that could place the donor at increased risk. Hypertension, diabetes, cancer and some infectious diseases can disqualify a potential donor. Obesity at certain centers can disqualify a potential donor due to increased risk of complications with anesthesia and post-operative healing. A weight reduction and smoking cessation program may be a pre-requisite.

During the psychological evaluation, the transplant center social worker or psychiatrist will determine the donor's motivation to donate, make sure the donor is aware of all potential outcomes, rule out substance abuse, emotional or competency problems and provide another opportunity for the donor to back out. Everything the donor says during this part of the evaluation is kept confidential.

The selection process is so rigorous that a recipient should not just have one potential donor on hand. The more potential donors the recipient can have tested, the greater the likelihood that one of those potential donors will be able to actually donate a kidney.

Are there any risks involved with being a living donor?

A donor faces the same risks he or she would face with any other major surgery. These risks include bleeding, infection, blood clots, post anesthesia complications and in some very rare cases, death. A free medical evaluation is often considered a benefit but the risk may be the unexpected discovery of an undiagnosed medical condition such as diabetes, cancer or other chronic disease.

Although some donors experience a slight increase in blood pressure, research has shown that kidney donation does not damage the donor's long-term health. Donors do not seem to be at increased risk of developing kidney disease and donors can still go on to have healthy babies.

Are donors at greater risk for developing kidney disease?

While research has shown that donors do not seem to be at greater risk than the rest of the population for developing kidney disease, there are no guarantees that a donor will not develop kidney failure due to an acquired injury or some unforeseen medical condition. Donors are encouraged to have annual physical exams so that their blood pressure and kidney function can be monitored.

Each potential donor will be screened carefully for kidney disease or the pre-disposition to kidney disease. The donor's current health status, past medical history and family history are all thoroughly reviewed. The ability to predict who is at risk for developing kidney disease when there are no predisposing factors is difficult. Kidney function studies and other specific studies as listed below are a significant part of the evaluation process:

- ◆ 24 hour urine creatinine clearance and urinary protein,
- ◆ renal ultrasound,
- ◆ blood chemistries

Does it cost anything to be a living donor?

In most cases, the recipient's insurance should cover all of the medical expenses associated with donation including the medical evaluation, hospitalization, surgery costs and post-operative care.

Insurance will not cover the donor's travel and lodging expenses, child-care expenses, and lost wages for time away from work. Depending on which type of surgery the donor undergoes, recuperation time can take anywhere from 3 – 6 weeks. The Georgia Transplant Foundation offers financial assistance for living donors to help them cover some of these expenses.

Why does the donor's recuperation time range from 3 to 6 weeks?

Recuperation time is different for each patient but the reason there is such a wide range in the number of weeks is that there are two types of surgical approaches to removing the kidney from the donor.

One approach is called an open nephrectomy and it involves a long incision along the donor's flank. Recuperation from this type of surgery takes 4 – 6 weeks because of the size and location of the incision.

The other widely used approach is called laparoscopic surgery. This technique involves 4 much smaller incisions around the donor's abdomen. Recuperation from laparoscopic surgery generally takes 3 – 4 weeks.

What should someone do if they are interested in donating?

After a patient has been evaluated and found to be an acceptable candidate for transplantation, the potential donor should contact the patient's Transplant Coordinator.

During the initial contact the coordinator does a brief medical screening to establish blood type compatibility between the recipient and the potential donor. What this means is:

| If the Recipient is: | The Donor must be: |
|-----------------------------|---------------------------|
| Type O | Type O |
| Type A | Type A or Type O |
| Type B | Type B or Type O |
| Type AB | Types AB, A, B, or O |

The rH factor is not important when it comes to establishing blood type compatibility, so for example, someone who is type A- could potentially donate to someone who is type A+ and vice versa.

Are there other tests to establish compatibility?

Yes, HLA typing is done to establish antigen identification and a crossmatch is done to determine antibody compatibility.

What are antigens?

Human Leukocyte Antigens (HLA) are proteins on white blood cells. A child inherits three antigens from each parent. Nearly 600 different antigen molecules have been identified.

An HLA “match” is the number of antigens that two people have in common. An “identical match” means all six antigens match, a “half match” means three out of six antigens match and a “complete mismatch” means there are no matches. The greater the number of matching antigens, the less likely the recipient’s immune system will see the donated kidney as “foreign” thus reducing the chance for rejection.

Here is an easy way to illustrate HLA matching combinations. In the following example of family typing, each parent has two sets of antigen groups. The mother has (1,2,3) (4,5,6) and the father has (7,8,9) (10,11,12). Each of the four offspring has inherited his or her own combination of HLA molecules noted by the numbers under each child’s name (Anne, Bob, Carol and Paul). Anne is the potential recipient, with Carol being an “identical match”.

| | | | | |
|--|--|--|---|--|
| | Mother (1,2,3) (4,5,6) | Father (7,8,9) (10,11,12) | | |
| Ann (1,2,3) (7,8,9) Patient | Bob (1,2,3) (10,11,12) Half Match | Carol (1,2,3) (7,8,9) Identical Match | Paul (4,5,6) (10,11,12) No Match | |

It is important to note that any sibling has a 25% chance of being an identical match, a 50% chance of being a half match and a 25% chance of being a zero match.

Why is the crossmatch done?

The crossmatch determines antibody compatibility. An antibody is a protein made by the body’s immune system in response to a foreign substance. People can develop antibodies from a prior pregnancy, a blood transfusion, or a previous organ transplant.

A crossmatch mixes the recipient’s serum with the donor’s white blood cells to determine if the recipient has antibodies to the donor’s cells. Antibodies will injure and even destroy the donor’s cells. A crossmatch that is not compatible means the transplant cannot be performed because the recipient’s cells would destroy the transplanted kidney.

What happens after the initial contact with the Transplant Coordinator?

After the health status of the potential donor is established, the next step is to schedule the medical and psychological evaluations. Some transplant centers require an additional psychosocial evaluation. These evaluations usually require a hospital stay of two to three days.

After the evaluations are complete, if the potential donor is approved as a compatible donor, the transplant coordinator will schedule the surgeries so that they are convenient for both the donor and the recipient.

Is there a way for the potential donor or recipient to talk to someone who has already gone through the donation or transplantation process?

The Mentor Project is a program that provides one-to-one contact between “veteran” donors and potential donors as well as between “veteran” transplant recipients and those who are waiting for a transplant or have been newly transplanted. If the potential donor or recipient would be interested in talking to someone who has undergone a similar experience, a referral can be made by contacting the Mentor Project at 800-822-3148.

Appendix A – Statistics on living donation vs. cadaver donation

Cadaver Matches & 5 Year Graft Survival

| | |
|-----------------|-----|
| 6 antigen match | 72% |
| 5 antigen match | 69% |
| 4 antigen match | 66% |
| 3 antigen match | 66% |
| 2 antigen match | 65% |
| 1 antigen match | 62% |
| 0 antigen match | 59% |

Living Donor Matches & 5 Year Graft Survival

| | |
|-----------------|-----|
| 6 antigen match | 87% |
| 5 antigen match | 78% |
| 4 antigen match | 77% |
| 3 antigen match | 76% |
| 2 antigen match | 78% |
| 1 antigen match | 75% |
| 0 antigen match | 71% |

Bottom line: Any compatible living donor kidney is better than any compatible cadaver kidney.

5 Year Graft Survival of Living Donor Transplants

| | |
|-----------------|-----|
| parent | 76% |
| offspring | 74% |
| sibling | 81% |
| other relative | 77% |
| spouse | 74% |
| other unrelated | 77% |

Community Resources

National Kidney Foundation of Georgia – (770) 452-1539 or (800) 633-2339

The mission of the National Kidney Foundation of Georgia is to prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation.

The NKFG offers programs for patients and their families including:

- **Camp Independence** – an annual seven-day medically supervised camping experience held each summer for children aged 6-18 with kidney disease and kidney, heart, and liver transplants.
- **Living Donor Program** – a full-time staff member is available to offer education, advocacy and support to patients and their potential living donors.
- **People Like Us, Live** – a 6-session seminar for newly diagnosed individuals and their families.
- **Crisis Intervention Fund** – offers qualified dialysis and kidney transplant patients a maximum grant of \$150 each.
- **Medic Alert Jewelry** – offers individuals with kidney disease or kidney transplants a complimentary piece of emergency identification jewelry imprinted with important medical conditions, allergies, etc.
- **Patient & Family Council** – offers patients, families and their healthcare providers a way to have a unified voice when it comes to making sure that kidney patients receive the finest possible health care.
- **Transaction Council** – provides advice, assistance and a unified voice to individuals with organ transplants.
- **Donor Family Council** – dedicated to serving the families of deceased organ donors.
- **Living Donor Council** – offers living organ donors a way to publicize living donation and work to improve the living donation process.
- **Team Georgia** - team members compete in the *U.S. Transplant Games*, an Olympic-style athletic competition held every other year. Members and supporters work year round to increase organ donor awareness.
- **Information Assistance** – the NKFG office has a library of information related to kidney disease as well as a catalog of brochures covering everything from coping with kidney disease to nutrition tips for hemodialysis patients.
- **Capital Kidney Connection** – a free bi-monthly update of legislative and regulatory initiatives of interest to the renal transplant community. Available by calling (800) 889-9559.

Georgia Transplant Foundation – (770) 457-3796

The mission of the Georgia Transplant Foundation is to help meet the needs of organ transplant candidates, recipients and their families by providing information and education regarding organ transplantation, granting financial assistance and being an advocate for sustaining and enriching lives everyday.

The GTF offers programs for patients and families including:

- **Financial Assistance** – programs for transplant candidates and recipients, offer emergency assistance, as well as assistance with housing, dental, insurance, pre-transplant.

➤ **Scholarships** – awards 2 scholarships annually, one to a transplant recipient and one to a dependent for post-secondary education.

➤ **Fundraising assistance** – program provides matching funds and fundraising guidance for those who must fundraise for their transplant medication costs or other costs related to transplant.

➤ **Wellness Conference** – annual fall conference in Atlanta for transplant recipients and their families.

➤ **Living Donor Assistance** – assists with donor related non-medical expenses.

Medication Access Program (MAP) – (706) 721-0131

The mission of the Medication Access Program is to increase access to medications for solid organ transplant patients who reside in the State of Georgia. This program seeks to educate patients and healthcare professionals about the availability of medication assistance programs and assist in the enrollment of patients in appropriate programs.

The Mentor Project – (770) 729-8003 or (800) 822-3148

The Mentor Project’s mission is to provide one-to-one contact between “veteran” donors and potential donors as well as between “veteran” transplant recipients and those who are waiting for a transplant or have been newly transplanted. Anyone interested in getting a mentor must be referred to the Mentor Project by a social worker, a clinical coordinator, a clinical nurse specialist or a physician.

The American Kidney Fund – (770) 395-6211

The mission of the American Kidney Fund is to provide direct financial assistance for the benefit of kidney patients supported by comprehensive educational programs, clinical research and community service projects.

The AKF offers programs for patients and families including:

➤ **Financial Assistance** – helps needy kidney patients pay for treatment necessities not covered by Medicare.

➤ **Renagel Patient Assistance** – provides 2000 low-income hemodialysis patients with a free 6 month supply of Renagel.

➤ **Health Insurance Premium Program** – helps low-income dialysis patients continuously maintain their healthcare coverage.

➤ **Direct Patient Grants** – provides financial assistance to patients who have exhausted all other sources of assistance.

Southeastern Kidney Council – (919) 855-0882 or (800) 524-7139

The mission of the Southeastern Kidney Council is to improve the lives of patients with or at risk for end stage renal disease by promoting and advancing quality of care.

The Council offers assistance to patients and their families in the following ways:

➤ **Grievance Procedure** – provides an objective, third party authority for patients who wish to complain about their ESRD treatment facility but are intimidated or afraid of reprisal. The grievance process encourages open communication between patients and ESRD facility staff regarding issues, problems or complaints from patients.

➤ **Information Assistance** – a library of materials related to kidney disease is available for distribution or loan to patients and healthcare providers.