

Transplant Liaison Resource Manual:

Resources for transplant education,
evaluation referral, patient status changes and submission
of laboratory samples

Prepared by:

The Transplant Committee of the
Maryland Commission on Kidney Disease and Transplantation

December 2007

Table of Contents

Introduction	3
Accomplishments: October 2006-2007	4
Updates on Patient Status	5
Kidney Transplant Contact Lists	9
The Referral and Evaluation Process and Referral Criteria	11
The Social Worker's Role in Transplantation	17
What the Transplant Liaison Can Do to Help Patients	20
UNOS/OPTN and the Waiting List	21
Tissue Typing	24
Dialysis Unit In-Services	30
Frequently Asked Questions About Kidney Transplantation	31
Appendix A: Transplant Centers' Patient Education Materials	
Appendix B: 2006 Promoting the Partnership Symposium Report	

Introduction

In the spring of 2005 the Department of Health and Mental Hygiene Commission on Kidney Disease and Transplantation began working with the Maryland transplant centers and outpatient dialysis units to focus on the partnership between these entities. The Commission created a “Transplant Committee” made up of Commission, transplant center and dialysis facility representatives. The initial objective of the committee was to develop an education symposium for the renal community.

The Commission endorsed the Mid Atlantic Renal Coalition’s Goals and Recommendations as a template for the symposium. The recommendations state that 100% of the dialysis facilities should designate one staff member to serve as the transplant liaison. The duties of the transplant liaison include oversight of transplant education, evaluation referral, patient status changes and submission of laboratory samples. The Commission requested that each dialysis facility appoint a transplant liaison to serve in this capacity.

As a result of the Transplant Committee’s work, a symposium on transplant and dialysis center communication was held on October 3, 2006. This seminar was designed to address the needs of the dialysis facilities’ transplant liaisons, and include topics such as the transplant evaluation process, tissue typing, indications and contraindications for transplant and post-transplant education. (See report in Appendix B of this resource manual)

In August 2007, the Transplant Committee decided to develop a resource manual that would be distributed to each dialysis facility. The contents of this manual include frequently asked questions, transplant center contact information, information on the referral and evaluation process, patient status and reporting information, how the transplant list works, patient educational materials and in-service request information. The Transplant Committee welcomes suggestions for future updates of this manual.

We hope that this resource manual will provide further support to the transplant liaisons and foster open lines of communication between the dialysis facilities and the transplant centers.

Accomplishments: October 2006 - 2007

The symposium in 2006 was the start of closer collaboration between both transplant centers and the state's many dialysis units. The Johns Hopkins program initiated regular *general information sessions* after hearing the questions expressed by the dialysis unit. These information sessions are currently being presented at Hopkins and in the dialysis units. The purpose is to explain the pros and cons of kidney transplantation and help patients and family understand what it's all about before they make the decision to pursue evaluation. In addition to a very general slide presentation, educational materials are made available to all who attend. These general information sessions have also been educational for some of the dialysis staff and feedback has been that it helps them answer questions their patients have.

In response to the ideas and questions discussed at the 2006 program, Johns Hopkins has offered an open invitation to all dialysis staff to attend our bi-monthly patient/family orientation program. This program is an all day program that is designed for patients and their families who are nearing transplant. In this program, presented by social work, nursing, surgeons, and a living donor, the detail of the transplant experience is reviewed, including medications and caregiver support issues. The program also includes a panel and a tour of the transplant facilities.

Another accomplishment that has brought the Hopkins program and dialysis liaisons closer together is the regular email contact that goes out every other month to the dialysis unit detailing the patients from that center on the Hopkins list or in workup. Because the contact email address and phone number for the transplant coordinator is listed on this email, the regular feedback as well as questions from the dialysis unit has increased. We know we are having more and more opportunities to talk with the dialysis units this way- about patients or just general questions.

Updates on Patient Status

The Johns Hopkins Hospital

The Johns Hopkins Kidney Transplant Program is committed to engaging in ongoing communication with patients' local dialysis facilities. This is done through phone, fax, email and U.S. postal mail at regular intervals during the course of the patients' care at Johns Hopkins. Our commitment to dialysis units includes the following:

- sending patient status updates on a bi-monthly basis to Maryland-based dialysis centers
- making patient status updates available, upon request, to any dialysis facility at any time
- sending a letter to the patient's dialysis center indicating that the patient has become active or inactive on the national organ waitlist.
- sending a letter and accompanying clinical notes to the patient's physician and dialysis facility indicating that the patient has been admitted or discharged for transplant surgery
- promptly responding to any inquiries from dialysis staff regarding the data contained in any correspondences sent to you

Dissemination of Patient Status List:

Every other month, Johns Hopkins emails the transplant liaison at each Maryland based dialysis facility a "Patient Status List" – this is the resource that helps dialysis unit staff track the status of your patients who are referred to the Johns Hopkins Kidney/Pancreas Transplant Program. The Patient Status List includes:

1. The patient's status, i.e., whether s/he is in referral, evaluation, or listed on the national organ waitlist.
2. If the patient has been listed on the national United Network for Organ Sharing (UNOS) organ waitlist: (a) the date that s/he was made active on the national list and (b) his or her current status (i.e., "active or inactive on the list")
3. The name and contact information for the evaluation or waitlist nurse coordinator who is currently managing the patient's care within the Kidney Transplant Program
4. The patient's contact phone numbers that have been reported to the Kidney Transplant Program by the patient and/or dialysis facility
5. The names of the patient's primary, secondary, and tertiary insurance providers (as applicable), that have been reported to the Kidney Transplant Program by the patient and/or dialysis facility

Refer to a sample Patient Status List on the following page.

Sample Patient Status List from Johns Hopkins

(Please note that patient identifying information has been blacked out on the sample in order to protect patient privacy.)

		The Johns Hopkins Comprehensive Transplant Center Baltimore, MD 21287 www.hopkinsmedicine.org/transplant		December 07, 2007		
Center Name: Davita - Aberdeen			Provider #: 212650			
JHH Liaison: Susan Humphreys						
UNOS						
Patient name	Status	Activation Date	RN Coordinator	Phone	E-mail	
.**-*	Active - Referral or Evaluation		Knott, Kate	410.955.5389	kknott1@jhmi.edu	
Contacts: Home-(410) [REDACTED] Work-(410) [REDACTED] Mobile-[REDACTED]						
Insurers: Primary Insurer: Blue Cr/Sh BEI Secondary Insurer:						
.**-*	Active - Referral or Evaluation		Humphreys, Susan	410-502-1685	shumphr3@jhmi.edu	
Contacts: Home-(410) [REDACTED] Work-/ Mobile-						
Insurers: Primary Insurer: Insurance Name: Medicare Secondary Insurer: Insurance Name: Aetna						
.**-*	Listed	10/30/2006	Rettaliata, Jane	410-502-4400	mrettal1@jhmi.edu	
Contacts: Home-(410) [REDACTED] Work-/ Mobile-						
Insurers: Primary Insurer: Medicare Organ Tx Secondary Insurer: Bankers Life and Casualty/Illinois						
.**-*	Listed	07/31/1996	Rettaliata, Jane	410-502-4400	mrettal1@jhmi.edu	
Contacts: Home-(410) [REDACTED] Work-(443) [REDACTED] Mobile-443-[REDACTED]						
Insurers: Primary Insurer: Medicare Organ Tx Secondary Insurer: EHP Basic Third Insurer: MA-Type PF #1						
Status Legend <i>Active - Patient is in the referral or evaluation stage of transplantation</i> <i>Listed - Patient is currently listed and waiting transplantation on the UNOS wait list</i> <i>Inactive - Patient is currently inactive on the UNOS wait list. Either medical or financial update is required.</i>						

Dissemination of Letter indicating Patient Status on UNOS list:

On the date that a patient is listed as an eligible candidate on the national organ waitlist, Johns Hopkins will send a letter to the patient and his or her local physician and dialysis facility informing them of the patient's "active" status on the UNOS list. This letter includes:

1. The date that the patient is listed as an eligible candidate on the national organ waitlist.
2. Instructions to the patient about sending in a regular blood clot serum for donor cross matching and a telephone number to call with additional questions about this procedure.
3. Instructions to the patient about informing the Kidney Transplant Program of changes in medical information, personal contact information, dialysis facility information, or residency; three alternative telephone numbers are provided to the patient to call with additional questions about this procedure.
4. Instructions to the patient about making appropriate arrangements for the Kidney Transplant Program to contact the patient via phone.
5. Instructions to the patient about informing the Kidney Transplant Program's Business Office of changes in insurance information and a telephone number is provided to the patient to call with additional questions about this procedure.
6. Instructions to the patient about how to contact the Kidney Transplant Program and/or UNOS about questions or concerns pertaining to the organ allocation process, transplant data, or issues pertaining to the transplant system. Kidney Transplant Program and UNOS patient services telephone numbers are provided.

Should an unresolved medical or financial event occur that would preclude the patient from being considered an eligible candidate on the UNOS list, Johns Hopkins will send a letter to the patient and his or her local physician and dialysis facility informing them of the patient's "inactive" status on the UNOS list. This letter includes:

1. The date that the patient is made "inactive," i.e., a non-eligible candidate on the national organ waitlist.
2. Instructions to the patient about ...
3. Instructions to the patient about how to contact the Kidney Transplant Program and a telephone number is provided to the patient to call with additional questions about this procedure.

Dissemination of Admission/Discharge from Transplant Surgery Letter:

Within five-to-ten business days after a patient is admitted to Hopkins for transplant surgery, Johns Hopkins will send a letter to the patient and his or her local physician and dialysis facility informing them of the patient's admission to the hospital and providing them with a set of clinical notes describing the patient's current medical status.

Within five-to-ten business days after a patient is discharged from the Hopkins for transplant surgery, Johns Hopkins will send a letter to the patient and his or her local physician and dialysis facility informing them of the patient's discharge from the hospital and providing them with a set of clinical notes describing the patient's clinical discharge summary.

Responses to Inquiries on Hopkins Access Line (HAL):

The Hopkins Access Line (HAL) is a consultation and referral service provided by Johns Hopkins Medicine. HAL's toll-free number - 1-800-765-5447- operational 24 hours a day, seven days a week - was created in response to the growing needs of clinicians to reach Hopkins physicians quickly. HAL gives practicing physicians and faculty the opportunity to assist one another in the diagnosis and care of patients.

All physician and dialysis facility calls are received by a HAL service representative. HAL representatives have access to Hopkins physicians' schedules, on-call lists, and telephone and pager numbers - all the numbers needed to reach the physician promptly. If a local physician or dialysis facility wishes to speak with a specific physician and he or she is unavailable, the representative will direct the caller to an available specialist or arrange for the requested physician to return the call.

Kidney Transplant Contact List

The Johns Hopkins Hospital

Name	Role	Email address	Phone number
Brigitte Reeb	Administrative Director	breeb1@jhmi.edu	410-614-5477
Jeanni Hines	Education and Outreach	jbarget3@jhmi.edu	443-287-2896
Rose Guerra	Affiliation Agreements	rguerra@jhmi.edu	443-287-2895
Mel Rodriguez	Surgeon Designee Agreements	mrodri17@jhmi.edu	410-614-0194
Liz Fisher	Tissue Typing	efisher3@jhmi.edu	410-955-3600
Susan Humphreys RN	Transplant coordinator supervisor	shumphr3@jhmi.edu	410-502-1685
Kate Knott RN	Evaluation coordinator	kknott1@jhmi.edu	410-955-5389
Carol Weaver	Evaluation coordinator assistant (with Kate)	cweaver5@jhmi.edu	410-614-6905
Roe Gall RN	Evaluation coordinator	rgall1@jhmi.edu	410-502-0704
Marvis Keech	Evaluation coordinator assistant (with Roe)	mkeech1@jhmi.edu	410-614-1164
Danielle Bonner	Referral/intake coordinator	dmara4@jhmi.edu	410-502-6152
Mary Kaiser	Social Worker	mkaiser2@jhmi.edu	410-614-2819
Angela Muir	Social Worker	amuir1@jhmi.edu	410-614-4442
Lakeisha Audain	Social Worker	laudain1@jhmi.edu	410-550-0294
Dennis Myers	Renal dietician	dmyers4@jhmi.edu	410-955-5787
Marcia Hardy	Waitlist manager		443-287-0520
Kathy Dane RN	Incompatible Transplant coordinator	kdane1@jhmi.edu	410-614-2988
Janet Hiller RN	Kidney swap program	jhiller1@jhmi.edu	443-287-4335
Athelene Henry	Living donor referral	ahenry3@jhmi.edu	410-614-6604
Kris Koelbel	Vascular Access Coordinator	Kkoelbe3@jhmi.edu	410-502-7921

Kidney Transplant Contact List

The University of Maryland Medical Center

Name	Role	Email Address	Phone Number
Benjamin Philosophe, MD, PhD	Division Head	bphilosophe@smail.umaryland.edu	410-328-1145
Laura Conroy, RN, BSN	Outreach Coordinator	lconroy@umm.edu	410-913-1429
Sue Ostovitz, RN, BSN, MBA	Transplant Administrator	sostovitz@smail.umaryland.edu	410-328-1715
Deb Evans, RN	Senior Pre- Transplant Coordinator	devans@smail.umaryland.edu	410-328-9145
Tina Stern, RN, BSN	Senior post- transplant coordinator	tstern@smail.umaryland.edu	410-328-9145
Eric Thompson, LCSW-C	Social Worker	ethompson@smail.umaryland.edu	410-328-7518
Chelsea Quinn, LCSW-C	Social Worker	cquinn@smail.maryland.edu	410-328-5008

The Referral and Evaluation Process

The Johns Hopkins Hospital

The Referral/Intake Coordinator is **Danielle Marable-Bonner, tel: 410-502- 6152.**

Referrals can come to Johns Hopkins through any means and by any person. We welcome self-referrals or referrals by family members, faxes or emails. Voice mails are returned no later than the next business day. If someone is not sure they want to refer themselves, and they just want to ask questions about the process, Danielle will usually have a nurse talk with that patient because they usually have clinical questions.

There are a number of special transplant programs managed through the Incompatible Kidney Transplant Program (InKTP). These programs include:

- Positive crossmatch transplant
- Blood-type Incompatible transplant
- Kidney Paired Donation (Exchange) transplant
- Non-directed (Altruistic) donor program

The Referral/Intake Coordinator handles all referrals and will triage candidates to the special programs, as appropriate.

When a referral comes in, some general information is requested about the patient's kidney disease, whether or not they are on dialysis, demographics and insurance questions. This general screening information is put into our database, and then a packet of information is sent out to the patient. Included in this packet is a description about the evaluation process and clear directions for what the patient is to do. One of the items in the packet is a recipient questionnaire, another is an evaluation consent form, and another is a release of information page. There is a letter describing what needs to be signed and returned to us. Patients are asked to send the release to their physicians and the clinical records are sent to our office.

When the clinical records, signed consent, and recipient questionnaire are received in the transplant office, they are reviewed by a nurse. When these documents are complete, Danielle calls the patient to schedule the evaluation. Information expected includes a recent set of labs and physician note from the nephrologist/dialysis unit, dialysis unit social work and nutrition notes, PCP information, including routine health screenings, cardiology testing and physician notes, records from recent hospitalizations, and clearance from any major health problem (such as a history of prostate cancer, etc.)

When the patient comes for their evaluation appointment, we tell them to expect to be at the outpatient center for a period of four hours. During the appointment they will see the nurse coordinator (for nursing assessment and education), social worker (for psychosocial evaluation), financial coordinator (for financial counseling), nephrologist, transplant surgeon and dietician. The patient will usually have blood drawn before leaving the outpatient center.

Following their appointment, they receive a letter detailing any additional testing that they need to have completed in order to be put on the waiting list or scheduled for living donor surgery. A copy of this is sent to the nephrologist and the dialysis unit.

Referral Criteria for Kidney/Pancreas Transplantation

The Johns Hopkins Hospital

The kidney/pancreas transplant team is committed to continually improving our partnership of care and communication with our healthcare colleagues.

Below are the general referral criteria for kidney transplantation and for pancreas transplantation that physicians may use as guidelines for referring patients to our program. Should you have a question about our referral criteria, you may contact any of the kidney/pancreas transplant physicians by calling our Hopkins Access Line (HAL), a 24-hour telephone service for community physicians at 410-955-9444 or you may contact Susan Humphreys, the transplant coordinator supervisor at 410-502-1685.

Kidney Transplant Referral Criteria

Any condition that results in end-stage renal disease, including, but not limited to:

- Diabetes mellitus
- Hypertension
- Glomerulonephritis
- Hereditary kidney diseases
- Congenital urinary tract defects

Absolute contraindications may include:

- Advanced cardiopulmonary disease
- Active malignancy with the exception of skin cancer
- Severe local or systemic infection
- Severe neurologic deficits
- Active substance abuse
- Untreatable psychiatric illness

Relative contraindications may include:

- Multiple urinary tract reconstructions
- Neurogenic bladder
- Lack of family or social support
- Severe malnutrition/cachexia
- Evidence of significant non-adherence
- HIV positive

High risk factors

These factors are evaluated on a case-by-case basis and do not necessarily preclude transplantation:

- Hepatitis
- Small size
- Complex genitourinary anomalies
- Neurogenic bladder
- Ileal loop
- Multivisceral transplant
- Peripheral vascular disease

Pancreas Transplant Referral Criteria

Dr. J. Keith Melancon, Director of the Kidney/Pancreas Transplant Program is personally dedicated to speaking with individuals interested in the pancreas transplantation program. Should you wish to speak with Dr. Melancon about the possibility of pancreas transplantation for a patient, please contact his office at: 410-614-0194.

HIV Transplant Referral Criteria

The Johns Hopkins Hospital is participating in a multi-center NIH-sponsored trial to study transplantation in patients with stable HIV disease who develop kidney or liver failure. Preliminary results from other sites show promising patient and graft (organ) survival, with excellent control of the HIV disease after transplantation. The most up to date inclusion criteria for the HIV transplant study may be found on our website <http://www.hopkinsmedicine.org/transplant/ID/HIVStudy.html> or by speaking with Susan Humphreys, the transplant coordinator supervisor at 410-502-1685.

Hopkins Access Line (HAL)

1-800-765-5447

(Continental United States)

410-955-9444

(Baltimore area and international calls)

Substance Addiction Protocol for Transplant Evaluation

The Johns Hopkins Hospital

To prevent recidivism, substance abuse must be appropriately addressed prior to transplant, and any patient who falls into the DSM III or IV criteria for addiction will be expected to enroll in an approved substance abuse program prior to being evaluated by The Johns Hopkins Hospital Transplant Team. An interventions counselor is available to provide lists of programs and monitor compliance.

The interventions counselor will determine the appropriate treatment program for the patient based on their assessment. Recommendations include: 90 day education/relapse prevention programs, in-patient treatment, 6 to 12 months of outpatient treatment and/or random toxicology screens. Acceptable treatment programs should be at least 3-12 months in length and include individual counseling and routine screening for active substance abuse. Treatment programs must discuss avoiding medications containing alcohol and “near” beers. For alcohol abuse, routine screening should include a Breathalyzer test on each visit and include random urine screening for illicit drugs at least once a month. For drug abuse, routine screening should include random urine screening for illicit drugs at least once a month. Treatment programs will be requested to send monthly updates on the patient’s progress.

Patients will not be transplanted until the interventions counselor has concurred that the patient is compliant with treatment recommendations and has been abstinent. The Transplant Team informs patients that any recidivism will prevent their activation on the transplant list or necessitate their inactivation on the list.

Patient Adherence:

Pre-Transplant

- Assessed by social worker and team during initial evaluation
- Emphasis is placed on education
- Compliance issues are addressed with a compliance-monitoring program. Written reports are required from referring center regarding adherence to treatment regimens.

Post-Transplant

- Coordinator and social worker focus on compliance
- Tools to monitor compliance: keeping appointments, immunosuppressive medicine levels, evaluating prescription use/re-fill request
- Interactions with primary health care provider

I. PROCEDURE - Initial Evaluation:

During “cold call” or initial contact, information (PHI) is collected by the PSC and entered into the information system. The patient is sent a packet of educational and patient rights materials as well as a schedule of events for the first evaluation appointment. This appointment includes:

6. Blood work
7. Nephrological consultation
8. Surgical consultation
9. Dietary consultation
10. Social work consultation
11. Nurse coordinator consultation

The kidney evaluation transplant office requests the following information from the referring physician/institution:

- Recent clinical summary, including all current medications and treatment plans
- Current nursing care plan
- Recent labs
- Social work evaluation
- Several recent dialysis flow charts
- Completed transplant office candidate checklist
- All demographic and insurance information
- Blood transfusion records
- Recent EKG, chest x-ray, renal sonogram, and renal biopsy, if available
- Results of GYN exam with pap smear within past year for females 18 or older
- Mammogram for females over 40

Information is forwarded at this time via database and direct communication to the finance office for patient insurance verification and validation.

The Social Worker's Role in Transplantation

Transplant social workers are involved throughout the transplant process, from the time of evaluation through any post-transplant care needs. Transplant social workers conduct an ongoing assessment of the patient and provide education, support and resources based on identified needs. Referrals to Social Work can come from all members of the multi-disciplinary team, including physicians, nurses, transplant coordinators, dieticians, finance office personnel and physical and occupational therapists. Patients and families can self-refer to the transplant social worker. In addition, the social worker screens for social work service needs. Contact information for the transplant social workers is provided to all transplant patients.

Pre-Transplant

During the evaluation process, a social worker provides education, information and counseling regarding psychosocial aspects of transplantation. Areas addressed include realistic and unrealistic expectations of transplantation, patient responsibilities, coping needs of recipients and families, understanding of systems involved in transplant, medication and pharmacy issues and financial considerations. In addition, resource information is supplied, including support resources and peer support opportunities. Counseling and/or referral to community agencies is provided as needed.

The social worker conducts a psychosocial assessment on all transplant candidates. Assessment is an on-going process, from the initial contact to post-transplant care. This evaluative process is used to identify potential obstacles to successful transplantation. Areas addressed in the psychosocial assessment for pre-transplant patients include:

- Current and past substance abuse; includes drugs (prescription and recreational), alcohol and tobacco
- History of adherence to the medical regimen (willingness, ability). Non-adherent patients risk failed transplants
- Family involvement/social support system. Patients must have a good support system in place to meet their emotional needs, as well as their physical needs both pre and post operatively
- Availability of a caregiver
- Transportation plan/resources
- Financial resources and/or financial issues
- Insurance and prescription coverage
- Adjustment to illness; coping (with loss sadness, crisis, role and life changes)
- Strengths
- Motivation for transplant
- Understanding of disease process and systems involved
- Expectations of treatment
- Employment situation
- Interests and activities, religion
- Advance Directives

- Future goals
- Mental health history
- Legal history

If an issue is identified during the evaluation that may serve as a barrier to someone successfully managing transplant, the transplant social worker discusses it with the patient and shares this information with the transplant team. Information, education and resources pertaining to the issue are provided whenever possible. The transplant social worker may contact the patient's dialysis center to further collaborate. The social worker will also follow-up with patients prior to them being listed for transplant or scheduled for surgery if a particular issue is identified. The transplant social worker remains available to the patient throughout their pre-transplant phase.

In-Patient Service

Social work services are provided to in-patients on the transplant service via referrals from the multi-disciplinary team, patient or family system or social work screening. New transplant recipients are screened to identify issues and/or barriers to adjustment and adherence with the post-transplant regimen. Some areas addressed are: social support, coping with transplant and hospitalization, financial and insurance resources.

The social worker does an assessment to identify interventions/services needed. Services provided include: support and emotional intervention to patients and families, education on psychosocial issues relevant to this phase of the transplant, resource information and referral. The social worker communicates with the multi-disciplinary team on psychosocial aspects and complications as appropriate.

The social worker assists with discharge planning. This may include home safety/support assessments and conducting family meetings. The social worker may facilitate placement for rehabilitation, assisted living/group homes, long-term care facilities, hospice and outpatient dialysis.

The social worker provides supportive counseling to patients and their families regarding feelings of grief and loss associated with their health status. Also addressed are adjustment issues related to changes in the level of support and supervision needed, prolonged hospitalization, self-image and self-esteem.

Post-Transplant / Outpatient Service

Issues requiring the social worker's intervention post-transplant include acquisition of medications, insurance issues and assisting patients with complicated psychosocial issues such as very limited financial or insurance resources, blindness and other disabilities that are obstacles to maintaining the transplant regimen, compliance issues, substance abuse, little or no social support, cognitive deficits and/or behavioral/psychiatric complications.

Post-transplant services begin with identification of a problem and/or referral to the Social Worker. Interventions include counseling and support, education, information and referral,

linkage to community resources and material assistance (grants, patient assistance programs, etc.)

Johns Hopkins Hospital

Pre-Transplant, In-patient, and Post Transplant Social Workers:

Mary Kaiser, LCSW-C 410-614-2819
mkaiser@jhmi.edu

Angie Muir, LCSW-C 410-614-4442
amuir1@jhmi.edu

Johns Hopkins Bayview

Pre and Post Transplant Social Worker:

Lakisha Audain, LGSW 410-550-5356
laudain@jhmi.edu

University of Maryland Medical Center

Pre-Transplant Social Workers:

Eric Thomson, LCSW-C 410-328-7518
ethompson@smail.umaryland.edu

Chelsea Quinn, LCSW-C 410-328-5008
cquinn@smail.umaryland.edu

In-patient Social Workers:

Shelley Cheatham, LGSW 410-328-7190
(works w/ patient's whose last name begins w/ A-M)

Zendy Williams, LCSW-C 410-328-1562
zwilliams@umm.edu
(works w/ patient's whose last name begins w/ N-Z)

Post Transplant Social Worker:

Chelsea Quinn, LCSW-C 410-328-5008
cquinn@smail.umaryland.edu

Live Donor Social Worker:

Nina Schroder, LCSW-C 410-328-2996
nschroder@smail.umaryland.edu

What the Transplant Liaison Can Do To Help Patients

There are many challenges that patients face once they receive their transplant. The transplant team's goal is to help patients prepare for these challenges in advance in order to make their transition to life after transplant as smooth as possible. The transplant team provides information and education to the patient during the evaluation and throughout the process. The Transplant Liaison at each dialysis unit can help the patient by:

- Encouraging patients to bring their support people to the pre-transplant evaluation
- Reminding patients to bring any recent medical tests, discharge summaries, labs, etc. to the pre-transplant evaluation
- Reminding patients that the pre-transplant evaluation is an ALL DAY appointment
- Reminding patients to bring ALL of their insurance cards (Medicare A,B, & D, Supplements, Veteran's Assistance card, Kidney Disease Program "KDP" of Maryland, private insurance)
- Alerting the transplant center of any major changes in patient's medical status, insurance, housing, employment, social support, etc.
- Encouraging patients to be as independent as possible with financial and insurance resources. Ex: completion of KDP application independently. This will help make the transition after transplant less difficult.
- Informing the transplant center of any compliance issues with dialysis. Behaviors pre-transplant are a good indicator for potential post-transplant problems.
- Informing the transplant center of significant mental health or substance abuse issues. Also, providing information on unresolved legal issues that have the potential of interfering with post transplant after care.
- Reminding patients that they must have a reliable transportation plan in place. Transportation can be a challenge for many patients. The transplant center can assist a patient with their MTA application, but cannot offer transportation or financial resources to pay for transportation. The post-transplant appointments are quite frequent and reliable transportation is essential.

UNOS/OPTN and the Waiting list

Often the question is asked, “Where am I on the national wait list?” or “Where is my patient on the wait list?” This is a very difficult and often impossible question to answer with definitive fact. The national wait list the patient waits on for a transplant needs to be looked at as fluid moving entity, ever moving and growing rather than a fixed check off sheet.

The key to understanding the transplant process and how a patient ultimately gets transplanted requires a general understanding of the regulatory framework and structure.

Transplantation is a highly monitored and regulated service/science. Placement of organs in the United States is done via a centralized process. This process is maintained with the strictest of policies, regulation and oversight.

At the head of the process is a governmental body overseen by the Department of Health and Human Services’ Health Resource Service Administration (HRSA) called the Organ Procurement/Transplant Network (OPTN). The OPTN was established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984. The OPTN is ultimately responsible for the development, management and enforcement of policy and the direction of transplantation in the United States.

Contracted by the OPTN is the second organization that must be understood to understand the transplant process. Contracted by the OPTN first in 1986, the United Network of Organ Sharing (UNOS) provides a backbone to the organ evaluation and placement process. UNOS has the responsibilities of:

- Collecting and managing data about every transplant event occurring in the United States-Facilitation of the organ matching and placement process through a central database (UNET)
- Bringing together medical professionals, transplant recipients, and donor families to develop organ transplantation policy
- Providing data to the government, public, researchers, and the Scientific Registry of Transplant Recipients (SRTR) for use in the ongoing quest for improvement in the field of solid organ transplantation
- Providing professional and public education about donation and transplantation, the activities of the OPTN and the need for donation

Under federal law, all U.S. transplant centers and OPOs must be members of the OPTN/UNOS to receive any funds through Medicare. Currently, every transplant hospital program, organ procurement organization, and histocompatibility laboratory in the U.S. is a UNOS member.

Other professional, scientific, community and patient organizations may also be members of UNOS (AMA, American Diabetes Assoc., ethicists, donor families, etc.)

The transplant process works within this structure. The process begins with a thorough evaluation which is explained elsewhere in this document. Once screened and cleared for

transplant, the potential recipient's information is compiled and then entered into the UNOS information System. This is most commonly referred to as wait listing or simply listing. The patient will remain an active candidate for transplant as long as he or she remains on the wait list and continues to meet transplantation inclusion criteria. It is often the case based on the patient's past health or transplant center's policy that the patient continue to submit to annual screening and testing to verify eligibility. Additionally for potential kidney and pancreas patients, a blood sample (clot, sera, serum specimen) is needed at least every 30 days for antigen/antibody matching with the deceased donor.

The next hopeful step in the transplant process comes when a potential donor is identified or an organ is available outside the local area. In cases of local donors, the Organ Procurement Agency (Living Legacy of Maryland) enters donor information into the national UNOS transplant computer system, Unet.

With all donors, information is electronically matched with the transplant center waiting lists for each organ ("match run"). Potential recipients are ranked according to objective medical criteria (i.e. blood type, tissue type, size of the organ, medical urgency, time already spent waiting, etc.). Using the match of potential recipients, the OPO contacts the transplant center of the highest ranked patient, based on policy criteria, and offers the organ. If the organ is turned down, the next potential recipient's transplant center on the match list is contacted

All things considered, in most cases organ allocation follows this path:

- Local allocation (University of Maryland & Johns Hopkins Hospital)
- Regional allocation (Maryland, Pennsylvania, Delaware)
- National allocation (United States)

The order of the organ allocation offers is the key to why the question: "where is the patient on this list?" is impossible to answer with a definitive statement. The order of allocation follows the algorithm:

- Zero antigen mismatch – "6 antigen match"
- Local matching – per point system
- Regional- per regional list
- National – per point system

Patients are assigned points based on waiting time, match quality, PRA, and age category. The system is explained below:

- Waiting time – 1 point will be assigned to the patient waiting the longest and a fraction of a point thereafter
- Quality of match – antigen matches base on "DR" marker
- Panel Reactive Antibody (PRA) – 4 points for PRA > 80%
- Pediatric Candidates - <11 – 4 points; 12-18 – 3 points
- Donation status – 4 points if patient donated an organ in the past

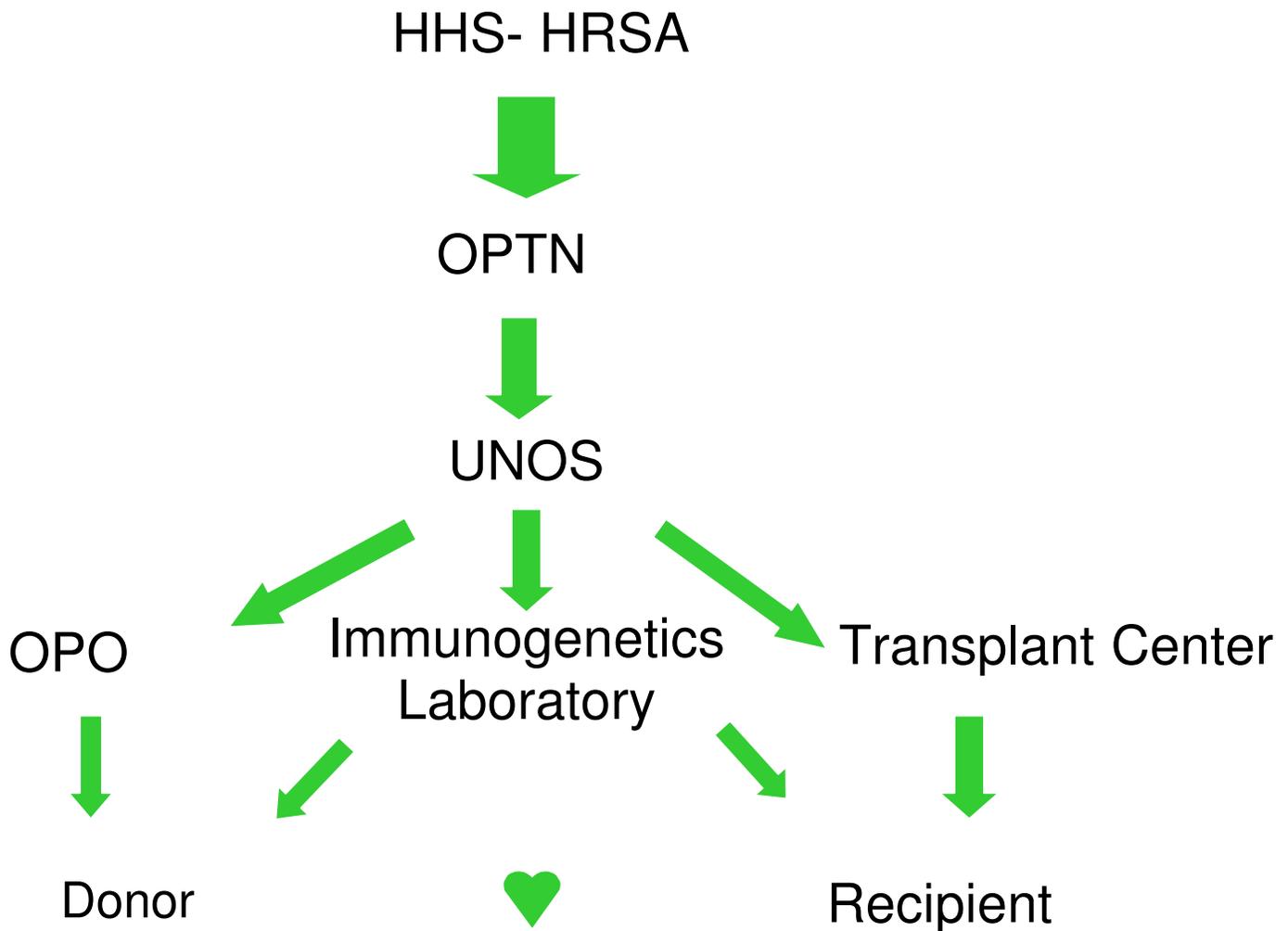
There may be special circumstances that apply to your patient that may shorten the wait.

Patients with positive serologies like Hepatitis B or C may be considered for donors with matching serologic positive profiles. Additionally, patients will be asked to consider expanded

criteria donors (ECD). These donors characteristically are older in age and may have had a health problem (high blood pressure, stroke) that may complicate the outcome of the transplant.

A movement is underway to improve the allocation system which will focus on the objective, *“Achieve the greatest good for the greatest number of recipients”*. This effort will take time to draft test and validate to avoid disparity and unfair practices.

The flow diagram below summarizes the process.



TISSUE TYPING

Kidney transplantation is the culmination of the efforts of many diverse and dedicated individuals whose expertise evaluates, maintains and ultimately transplants those patients

requiring a new kidney. Tissue typing or histocompatibility testing is one of the many behind the scenes activities involved in the extraordinary process that culminates in the successful transplant. The goals of the laboratory are to rapidly determine the immunologic risk associated with a transplant, precise and efficient communication and the delivery of accurate results. Interestingly, the tissue typing laboratory relies on the coordinated efforts of the dialysis units, the transplant centers and the organ procurement organizations to deliver the results necessary to transplant patients.

Histocompatibility testing involves three main areas: HLA typing, antibody screening and crossmatch testing. HLA typing provides the information for matching a particular recipient with a potential donor. Antibody screening testing tracks the patient's sensitization against antibodies that may be harmful to the transplanted kidney. These antibodies can lead to the rejection of the kidney. It also provides an indication of the likelihood that a particular donor kidney will be compatible with the patient. Finally, the crossmatch test determines that a donor and recipient are compatible. The crossmatch test is always done immediately prior to the organ transplant.

Since the majority of patients with renal disease are on dialysis, the dialysis unit plays a vital role in the entire transplant process, particularly the monthly antibody screening performed on patients on the transplant waiting list. The monthly specimen is required for several reasons. There are immunological constraints, time constraints, geographical constraints and regulatory constraints. A monthly serum specimen allows the laboratory to develop an antibody history or immune profile on each patient. For example, this profile can change when a patient receives a transfusion during dialysis. It also allows the laboratory to meet the time constraints that are inherent in the transplant process where it is important to identify the potential kidney recipients in the shortest amount of time so that kidneys get transplanted as quickly as possible. Finally, the monthly specimen provides the sample that is often used in the crossmatch test done immediately before the transplant. In Maryland transplant patients are geographically spread across the state and can be several hours away from the transplant centers located in Baltimore. By having a monthly specimen in the laboratory, the final testing needed to determine the compatibility of the donor/recipient pair can be accomplished without transporting the patient to the transplant center unnecessarily. Imagine the thrill for a patient receiving a call that a kidney has been identified for them and all they have to do is come to the transplant center because all the preliminary testing has been completed and they are ready for transplant.

All potential transplant recipients waiting on the UNOS List are required to send a monthly serum sample for crossmatch with prospective donors and monthly antibody monitoring. This is where the regulatory constraints are evident. The volume of the monthly sample must be at least 10cc since the sample will be used for multiple testing assays. The sample must be properly labeled with the patient name, unique identifier such as their social security number or date of birth, the date the sample was drawn and the initial of the phlebotomist. If any of these criteria are missing the laboratory is obligated under Federal Regulations and national safety standards to reject the sample.

The tissue typing labs at both transplant centers provide kits for these specimens. These kits include the correct United States Post Office packaging for biological specimens, barcoded

labels for the patient's specimen, the required red top tube with no additive and prepaid mailing containers to send the specimens back to the appropriate lab. Once the blood is drawn and placed in the packaging, the kit can be dropped in any US post box for delivery to the lab.

Communication between the dialysis units through their transplant liaisons and the tissue typing laboratory decreases the barriers that may keep transplant patients from receiving a desired transplant. The coordination between the dialysis units and the tissue typing laboratory for the monthly serum specimen is just one example of the partnership that exists in Maryland to help patients who are waiting for kidneys while on dialysis.

Immunogenetics Laboratory

2041 E. Monument Street
Baltimore MD 21205-2222

MEMO

**To: Dialysis Centers
Patients on Home Dialysis**

**From: Jeff Sholander, MT(ASCP), MBA, CHS
Laboratory Manager**

Subject: Serum specimens on Transplant Patients

Date: January 1, 2007

All potential transplant recipients waiting on the UNOS List are required to send a monthly serum sample for crossmatching with prospective donors and monthly antibody monitoring. The volume of the monthly sample must be 10cc since the sample will be used for multiple testing assays. The sample must be properly labeled with the patient name, unique identifier (social security number, date of birth), date the sample was drawn and the initials of the phlebotomist. The Johns Hopkins Immunogenetics Laboratory provides, for your convenience, barcode labels for all active transplant patients. The labels have the spaces available for the required information. If any of these criteria are missing the laboratory is obligated under Federal Regulations to reject the sample. All patients will be required to send a monthly sample for deceased donor crossmatching and antibody screening.

Specimens must be drawn the first week of every month and sent to the laboratory no later than the 10th of each month. A reminder will be sent to each patient if a sample has not been received by the 10th of each month.

Attached are the protocols for specimen barcode label information as well as the use of the prepaid specimen mailers. I would like to stress the importance of the barcode labels. They reduce specimen handling, labeling errors and subsequent rejection of specimens, which directly affect patient care. If you need additional labels or mailers, please follow directions in the attached protocol.

Please be aware that these protocols apply to only those patients of the Johns Hopkins Comprehensive Transplant Center.

Thank you for your attention to these vital matters. Please call if you have any questions or concerns.

Immunogenetics Laboratory

2041 E. Monument Street
Baltimore MD 21205-2222

January 1, 2007

BARCODE LABEL INFORMATION

In an effort to positively identify the serum samples which are routinely sent to the Tissue Typing Laboratory we have developed bar-coded labels which the laboratory will supply to dialysis centers and patients active on the UNOS wait list. This is necessary because the Tissue Typing Laboratory maintains records on over 60,000 patients and it is not uncommon to have multiple patients with the same name. Also, we have experienced the common problems of labeling: illegible handwriting, incomplete names, and no secondary identifiers such as social security number or date of birth.

The information provided on the labels include the patient's first and last name, date of birth and social security number which is also barcoded. There are also spaces for the phlebotomist's initials and the date of sample collection. The label must be firmly attached to the tube. The long edge of the label must be parallel to the length of the vacutainer tube. Our scanner is unable effectively to read the label if it is positioned in any other manner on the tube.

In order for the system to work perfectly, the barcoded label must be used. If samples are received with illegible handwriting or lacking any of the required information, the sample will be rejected and the patient may not be eligible for a transplant. Approximately one month before you need more labels, fill out the information on the enclosed form and fax it to the laboratory (410-955-0431) or contact Liz Fisher (410-955-3600)

We request that you inform all personnel involved in phlebotomy about these labels, keep them in a convenient place, and use them each time you draw a specimen for the Tissue Typing Laboratory. If you have any comments or questions, please call.

Thank you for your attention to this very important matter.

MEMO

**To: Dialysis Centers
Patients on Home Dialysis
Patients Managing Monthly Specimens**

**From: Jeff Sholander, MT(ASCP), MBA, CHS
Laboratory Manager**

Subject: Prepaid Specimen Mailers

Date: January 1, 2007

Beginning January 1, 2007, the Johns Hopkins Comprehensive Transplant Center will provide pre-paid specimen mailers to patients and dialysis units for sending in the required monthly serum specimens on patients on the UNOS transplant wait list.

The kit will now include the following:

- Correct USPS packaging for biological specimens
- Barcoded labels for the patient's specimens
- A tube for the specimen
- Prepaid USPS labels for return shipment to the laboratory

After drawing the specimen, package the tube in the mailer, seal the box and drop it in any US Post Office box or have your mail carrier pick up the package. The package will be automatically routed to the Tissue Typing Laboratory at Johns Hopkins.

As a reminder, specimens must be drawn the first week of every month and sent to the laboratory no later than the 10th of each month. A reminder will be sent to each patient if a sample has not been received by the 10th of each month.

Until, you begin receiving the boxes with the pre-paid labels, if you contact the lab, they will be happy to provide labels for the boxes you have on hand. Contact Liz and tell her how many labels you require. Her contact information is:

Liz Fisher
410-955-3600-phone
410-955-0431-fax
efisher3@jhmi.edu

Please be aware that these mailers can be used only for patients of the Johns Hopkins Comprehensive Transplant Center. Please call if you have any questions or concerns.

Dialysis Unit In-services

The Johns Hopkins Hospital

Many dialysis units call and inquire about in-services for staff. In-services can provide a general overview of transplantation or provide a specific area of information, as requested by the dialysis unit. There are three nurses who are available to visit dialysis units to do an in-service. Each nurse is assigned to cover a group of dialysis units in a geographical area. You may call either Susan Humphreys (410-502-1685) or Jeanni Hines (443-287-2896) to schedule an in-service from Johns Hopkins.

Frequently Asked Questions About Kidney Transplantation

Process Questions:

Q: How does a patient get started if they want to get a transplant...can they self refer or must they be referred by the dialysis center or nephrologist?

A: Any of the above. Patients who are interested in transplantation, or providers who would like to refer a patient, can call the transplant center to set up an evaluation appointment. The Hopkins phone number for this is: 410-502-6152 or toll free 888-304-5069. The University of Maryland phone number for this is: 410-328-5408

Q: What is the sequence of steps that are taken in the assessment process from the time a referral is made until surgery is scheduled? How long does it take? Do you have any suggestions about how this process can be improved or made more efficient? Internally? Externally? How can social workers assist in this process?

A:

Steps involved –

1. Send in up-to-date (within last year) medical records that include history and physical, labs, and testing such as cardiac studies and routine health maintenance exams (colonoscopy, Pap smear, mammogram, PSA)
2. Send in a copy of insurance card (front and back)
3. The transplant center must get approval from your insurance company to see you for transplant evaluation.
4. The transplant center clinical team will review the records sent in to us
5. You will be seen for a consultation appointment with the transplant surgeon, social worker, dietician and nurse coordinator within 2 months time
6. You will receive a letter outlining any additional testing/consults to be done before being approved for listing or transplant (the dialysis unit and nephrologist will also receive a copy of this letter in hopes that they will help facilitate the testing if needed).

The requested testing should be completed within 90 days if possible. If a test has been completed previously, the results must be from within the last year. If the patient doesn't complete the testing in the first 90 days, a reminder letter is typically sent by the transplant program. If it is still not completed, the patient is usually removed from the evaluation process unless other arrangements are made.

There is an opportunity that exists for the patient's healthcare team, including the social worker, to identify the barriers facing patients who have difficulty in completing the testing within 90 days (for example, a patient may not have a primary care provider, and may rely on their dialysis unit staff and/or nephrologist to assist with facilitating the testing process). Communicating these barriers to the transplant center staff, or working with the patient to overcome these barriers, is very helpful.

Q: What are some examples of unexpected developments that can transpire during this process? Please give examples, including likely outcomes.

A: The transplant evaluation, or work-up, involves a thorough, multisystem evaluation with a lot of testing. Sometimes other diseases are discovered on X-Rays or lab work. Some examples of unexpected developments could include: incidental findings on a chest x-ray (possible tuberculosis or cancer, etc); work-up scans revealing a significant finding (e.g., thyroid nodule that needs to be biopsied or carotid ultrasound revealing need for intervention, etc.); need for a cholecystectomy; positive stress test requiring open heart surgery; findings of previously unknown Hepatitis B, C, or HIV; RPR+ (syphilis) to name a few.

Q: What are the similarities & differences between the deceased donor evaluation process and the living donor evaluation process?

A: The deceased donor is intensively evaluated in a short period of time. The necessary lab work, X-Rays, cardiac evaluation are done while the donor is in the intensive care unit. The social history about behaviors that may have health implications is taken from the next of kin. This is a very important interview, and requires the next of kin to be knowledgeable about health behaviors.

The living donor is approached first to assure that donating a kidney will, in no way, cause any harm to their current or future health. The living donor receives extensive medical assessment as well as a psychological evaluation. Laboratory testing and XRay exams are similar to the deceased donor, but occur over a period of time.

Q: Do all the requirements of the evaluation need to be complete before a patient is added to the deceased donor organ waiting list?

A: For the most part- yes.

Q: What percent of patients evaluated are accepted as transplant candidates?

A: An estimated 20% of patients who are evaluated for transplantation are not added to the organ waiting list. The most common reason that a patient is not added is that they do not complete their evaluation testing. The transplant centers are studying the reasons why this happens, and have begun to offer educational sessions to help these patients understand about transplant before they take the first step, so they know what they are getting into.

Q: What avenues do patients have to express complaints or grievances? Minor vs. major complaints? What resources should social workers be aware of at different stages in the process?

A: Patients are encouraged to contact the transplant team if any problems or concerns arise. Social Work is often consulted in regards to financial issues or if they cannot attain their post transplant medication. Social Workers are knowledgeable about support groups and are willing to brainstorm with the patient in order to identify ways to address their grievances. The

transplant center offers direct access to a manager when a patient has complaints about a team member or process. The manager will involve a patient relations representative if needed. Patients also have access to the Patient Relations department directly. If these avenues do not address the patient's concerns, they may access the United Network for Organ Sharing (UNOS) grievance line at 888-894-6361.

Q: Do recipients and donors have the same transplant coordinator? Why or why not?

A: Separate transplant nurse coordinators are assigned to the recipient and to the living donor to maintain objectivity, confidentiality, and to prevent conflicts of interest. As of June 2007, this division between the recipient and living donor clinical team is mandated by the Centers for Medicare & Medicaid Services (CMS).

Q: For patients who lose their transplant due to noncompliance, how readily will they be re-listed?

A: Usually once the non-compliance results in the loss of the transplant graft, the recipient realizes just what they have lost. Upon re-evaluation, the patient is checked for compliance as well as assessed by the transplant psychologist. Final input is also requested by the transplant team from the dialysis center social worker as well. Each circumstance is handled on an individual basis. If a living donor is to be part of the process, the recipient is made aware that his history of non-compliance needs to be shared with the potential living donor so the donor can decide if he still wants to proceed with the transplant.

Q: If a transplant is not successful (not due to rejection but because the kidney never functioned properly) what happens to the recipients status... does the patient need to be re-listed or do they maintain their previous placement on the list?

A: If a transplant graft does not function for any reason within the first 90 days (either the patient has to return to dialysis or has a GFR>20%), an appeal is made to the United Network for Organ Sharing (UNOS) with extensive documentation required so that their UNOS wait list time can be re-instated. They are usually made inactive on the list to allow healing (this allows the patient to continue to accrue wait time but is ineligible for immediate organ offers). Once cleared by the surgeon, they are re-instated to full active status and can accept organ offers.

Q: How long can a kidney safely be kept on ice before transplanting?

A: About 48 hours. Final decision is at the surgeon's discretion depending on the overall status of donor organ. Although the shorter the time on ice, the better it is believed the kidney will function, kidneys have been successfully transplanted with very good functioning, beyond 48 hours.

Recipient Questions:

Q: What are some examples (red flags) that would result in a potential recipient being screened out? What defines an ideal candidate? An acceptable candidate?

A: Red flags include active heavy alcohol use; active drug abuse; severe heart disease; untreatable or recurrent cancers. Patients may lack appropriate caregivers or have inadequate insurance to cover all the costs of transplantation. Patients may not have transportation to post transplant follow up appointments or have mental health issues that may not be adequately managed. The difference between ideal vs. acceptable varies from patient to patient.

Q: Are there any strict age limits imposed on the consideration of a transplant recipient? If yes, what are they?

A: Age is a variable number. Though not many, there are patients on the waiting list in their 80s. At the same time, some candidates younger than that may not be medically suitable for transplantation. An individualized review of their medical condition is needed. The only strict age limit required is for a pancreas transplant, where the recipient must be 55 years old or less to be eligible.

Q: Is it possible to reduce the chances that a non-adherent patient be approved for transplantation?

We are always striving to eliminate the possibility that a patient will not adhere to their medical regimen, especially when it means the potential loss of a very scarce and precious resource. All members of the team attend to this potential problem with an individual approach. One way to address adherence is through education, availability of clinicians for questions, and close monitoring of patients. If a dialysis unit representative is concerned about adherence issues with a potential transplant candidate, they are encouraged to contact the transplant center to relay and discuss the concerns.

Q: How do you address the concerns pertaining to a patient with a history of alcohol or substance abuse issues? Psychiatric/emotional disorder? Current vs. past behavior?

A: Patients must be alcohol or drug free for at least 6 months prior to transplant. If there is an extensive history of abuse, they must have successfully completed a rehabilitation program. Depending on the extent and duration of the abuse, is behavior in question active or in the past, has the patient been through formal rehab and/or counseling. Each circumstance is handled on an individual basis. Things to consider: any recurrence and what was the trigger if any, patient overall state of mind at the time of evaluation. Once we transplant the patient, we add certain meds which can cause potential mood swings and baseline mental status changes so we need to get as complete a picture of the candidate as possible pre transplant.

Q: How much exposure does a transplant candidate have to social work during the evaluation process and waiting period? What do social workers look for during the work up? What is the social worker's role?

A: A transplant social worker is available to patients and families during all phases of the transplant process. Before transplant, every patient meets with a social worker during their evaluation. At that time, a psychosocial history is obtained. The social worker is evaluating the patient's understanding of their illness and transplant, social supports, caregiving plan, financial

vulnerability, insurance resources, substance use/abuse and coping abilities. The goal of this evaluation is to identify any potential barriers to someone being able to successfully manage transplant. Social workers provide support, transplant education and information on pertinent resources. While awaiting transplantation, the social worker is available as needed for ongoing support and information. At the time of transplantation, the social worker meets with the patient to screen for potential issues, assess coping, provide support, offer information on resources and assist with discharge planning as needed. After transplantation, social work is available as needed to assist with social and financial issues related to transplant. The social worker is an integrated part of the transplant team, communicating with other members of the team throughout the transplant process.

Q: What are prime examples of non-adherent behavior? What are the consequences and how quickly can these consequences occur?

A: Some examples of non-adherent behavior that we have seen include: refusing to answer calls from the follow up transplant coordinator, not showing up for follow up appointments (including the doctor visits and completing the required lab work, etc.), not taking the prescribed immunosuppression medications. Depending on the exact course of action, consequences can be seen within days of discharge from the hospital that can result in irreparable damage to the transplant organ.

Q: Can adherent patients still have a rejection episode?

A: Yes, a rejection episode can happen to an adherent patient because rejection is not always a function of not taking the proper medications. Sometimes it is a reaction that the body takes independent of how careful the patient has been about adherence. However, the more adherent a patient is about completing the required follow up lab work and seeing his doctor, the more likely that rejection – if it does occur – can be detected early. This is important because it increases the chances that the rejection episode can be managed or reversed with today’s powerful medications.

Q: Can HIV + patients be given a transplant? If yes, must the donor also be HIV +?

A: There are about 10 centers working with HIV+ candidates for organ transplant in a nationwide NIH research study. Both of the transplant centers in the state of Maryland are participating in the NIH study. As there are several strains of the HIV virus, the donor must be HIV negative. For more information about the HIV+ Transplant Protocol at Johns Hopkins, please visit this web page: <http://www.hopkinsmedicine.org/transplant/ID/HIVStudy.html>

Q: What about patients with other communicable diseases or immunosuppressed conditions? Hepatitis? Cancer?

A: The transplant center performs transplantation in patients who have complex medical histories, including patients with communicable diseases (HIV and Hepatitis B and C) and complex medical conditions (SLE, Scleroderma, various types of vasculitis, etc). We work closely with the patient’s primary doctor and/or specialist. In some cases, as with Hepatitis, a

liver biopsy is required. If liver disease is extensive enough, the patient may be listed for both a liver and a kidney transplant.

Q: Can a patient request a particular surgeon when having a living donor transplant?

A: Yes, but due to various the busy clinical schedules of the surgeons, we can not make an absolute guarantee.

Q: What if a patient has not begun dialysis and has no insurance in place? What resources are available for patients with low incomes, little insurance?

A: A patient must have insurance in order to be transplanted. If insurance is not in place, there is a high likelihood that a patient will not be able to manage their newly acquired kidney since medical care is an ongoing process. This would indicate to the team that the patient may be at risk for losing their transplanted kidney due to not being able to get their medications. Social Workers and Transplant Financial Coordinators can make suggestions as to where insurance can be attained whether it be through Medicare, Medicaid, or if the patient is a Maryland resident, the Kidney Disease Program.

Q: What are the most important things for patients to know prior to deciding on transplant in order to make an informed decision?

A: Transplant is another form of treatment for ESRD, not a cure. And we can't want the transplant more than the patient does. The patient will need to be an active participant in their care. Patients need to make the best choice for themselves. Our social work team has seen some patients who want to make a decision to go through transplantation because a family member or significant other is pressuring them to do so. The patient needs to know what they're getting themselves into and make a decision for themselves.

Q: What if a patient changes their mind about being transplanted or wants to wait to decide?

A: There is no penalty for changing their minds or needing more time to make a decision. It is preferable for a patient to wait rather than make a rash decision. This is a major life decision requiring commitment and work.

Q: What do patients need to know if they are coming from out of state?

A: It is likely that out of state patients will need local housing as there is weekly follow-up once a week for six weeks once the patient is transplanted. They need to make sure that their insurance will cover procedures done at the transplant center. Patients with out of state Medicaid should know that it is unlikely that their medical bills will be paid in Maryland.

Donor Questions:

Q: How are potential living kidney donors evaluated? Please discuss the emotional and psychological considerations as well as the medical. What do you specifically look at in order to assess compatibility?

A: The potential donor himself/herself must call the Johns Hopkins living donor office (410-614-6604) or the University of Maryland (410-328-5408) and express interest. It is essential that the donor make the initial contact with our program. We get medical, social history and demographics. If there are no initial problems identified, we set up the donor up for tissue and blood typing. The living donor patients are called with their results. Results are not given to the recipient. We cannot disclose donor information to anyone other than the donor. A summary letter is sent to the potential donor with the tissue typing results.

If they choose to go forward as a donor, then we do screening tests: blood work and urine. If that is normal then they come to the transplant center for evaluation by a nephrologist, surgeon, and psychologist. During the evaluation appointment, the donor will also have a CT scan, chest Xray and EKG. If the testing is not normal, the donor is referred back to their primary care physician to get that issue cleared. If they receive clearance for the medical issue, then they can be reconsidered by our team. A history and physical is done by both a nephrologist and surgeon. Counseling is also done by both physicians with regards to the donor's risk and the procedure. The transplant nurse coordinator does pre and post operative teaching. If labs, CT scan, and other diagnostics tests are normal then the donor's case will be presented to the multidisciplinary team for final approval.

Emotional and psychological considerations- Nephrology discusses with the patient his/her relationship to donor. Psychology does in depth interview and has all donors complete a questionnaire. If necessary, someone from the transplant team will speak with the donor's primary care physician or psychiatrist for input.

The nurse coordinator discusses what is involved before going into the process- including issues the donor should consider about family, job etc. The team discusses these types of issues at final approval.

There is great psychological benefit to a donor. Most donors have a feeling of satisfaction after donation. However, some donors may experience sadness, disappointment, depression, guilt, or anger if the recipient has rejection or does not do well post transplantation. Donors who are not biologically related may be more likely to experience these feelings.

Compatibility: The first choice is to have a blood type compatible donor. Then we consider the antibody status of the recipient. Finally, we look at the 'HLA' or tissue type match. If a recipient has had a previous transplant, we look to see if the new donor has any of the genetic barriers that the previous donor had with the recipient.

Q: What are some examples that would result in a potential donor being screened out? What defines an ideal candidate? An acceptable candidate?

A: Donors are ruled out if they have :

Diabetes	Cancer
Are taking lithium	BMI > 35
African American with HTN	Have HTN and are <50 years of age
Angina	a history of 2 or more kidney stones
Kidney disease	Significant medical problems
Active substance abuse	strong family history of kidney disease, diabetes, or HTN
Anatomy issues	Infectious diseases

Donors will need further evaluation testing, but could be ruled out if:
There is a history of hematuria, certain cancers, or abnormal screening test results.

A donor needs to be healthy from a medical standpoint with low risk of developing any disease in the future that will affect kidney function. They need optimally have a BMI less than 30 with favorable anatomy for donation. No two people are the same, so we have to assess each donor with their unique medical and family history.

Q: How much exposure does a donor have to social work during the evaluation process?

A: Potential kidney donors are not seen by a social worker, but are seen by a psychologist who specializes in living donor issues. If a donor wishes to see a social worker in addition to the psychologist, arrangements will be made for this. A donor advocate is also available to meet with the potential donor. The donor advocate is separate from the transplant team and can provide an objective voice in the decision process.

Q: What criteria are used to decide whether to request a psychiatric evaluation?

A: It is a standard requirement that every donor is seen by our psychologist.

Q: Are there any strict age limits imposed on the consideration of a transplant donor? If yes, what are they?

A: A donor must be 18 or older to be considered for living donation. There is no strict upper age limit, however, the team looks at the kidney function and medical history of the donor. They also take into consideration the recipient's age. There have been living donors in their 70's who donated to someone about that same age. In general, the team avoids matching a 20 yr old living donor to a 70 yr old kidney recipient, if possible.

Q: What if a person changes their mind about donating or wants to wait to decide?

A: A donor can withdraw at any stage of the process. Living donation is a strictly volunteer process and the transplant team is careful to make sure that the living donors know that. The donor work-up is done at the donors pace. There is not a time limit to get testing done.

Q: How deeply do you explore the relationship between the donor and recipient?

A: The transplant team asks for the relationship at the initial interview. The transplant psychologist, nephrologist, and surgeon further explore the relationship when the patient is evaluated.

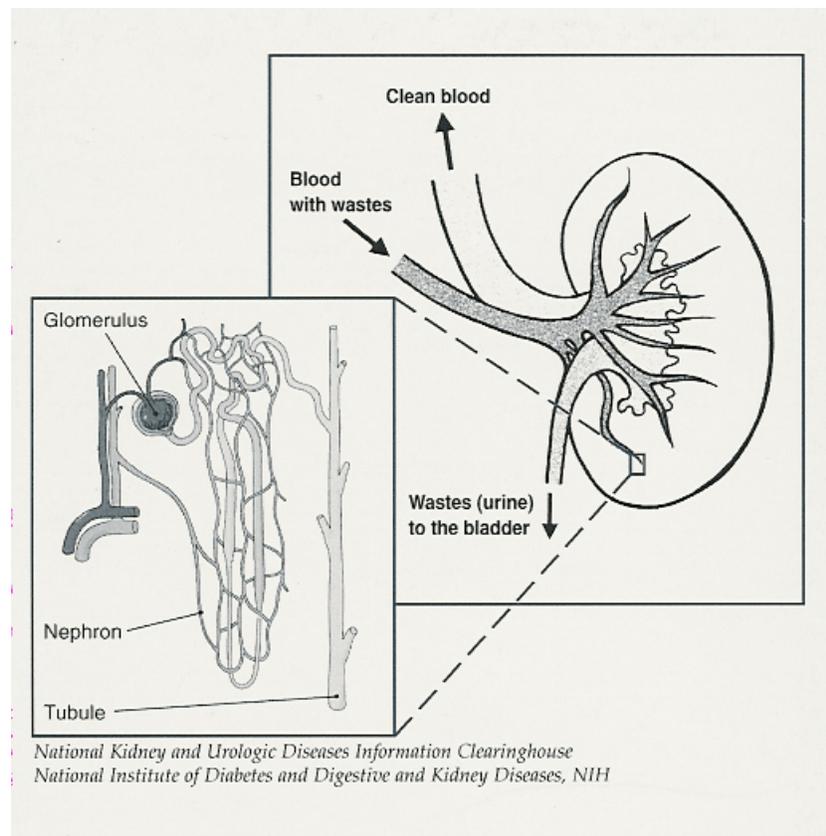
Appendix A:
Transplant Centers' Patient Education Materials

Understanding Kidney Function

Your kidneys are two organs that are located at the back of your abdominal cavity, one on each side of your spine. Your kidneys perform several life-supporting functions to keep your body healthy. These include:

- making urine to remove waste products from your body
- controlling the amount of water that stays in your body
- controlling your body chemistry and keeping the proper balance
- releasing hormones that help control your body's blood pressure, make red blood cells and maintain bones.

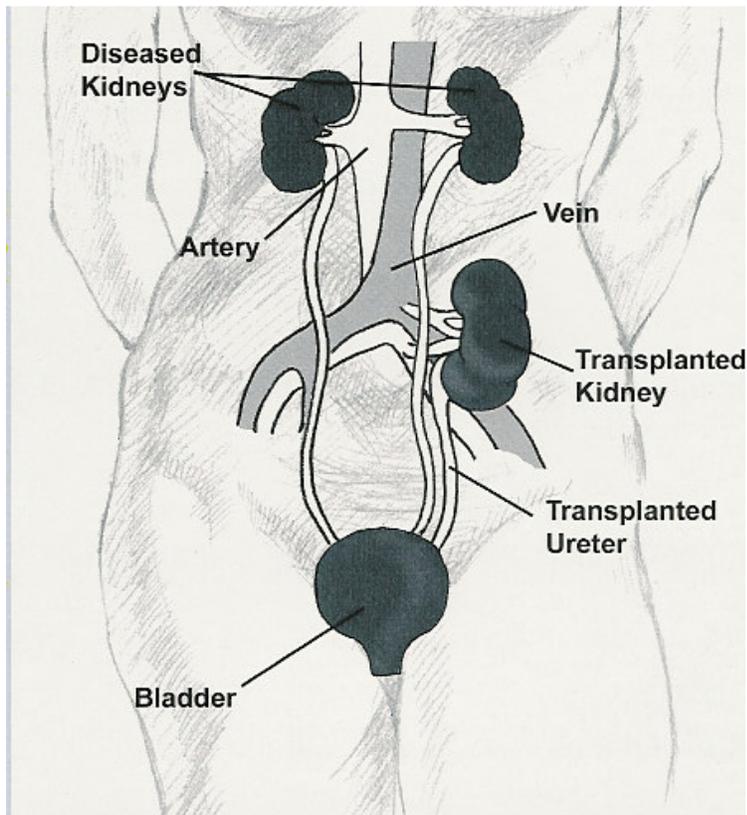
If your kidneys lose their function, waste products from your blood build up. This will make you sick. To rid your body of waste products, you will need to start dialysis or have a kidney transplant.



Kidney Transplantation: How It Works

A kidney transplant is a treatment option for end-stage renal disease. Kidney transplantation is a surgical procedure whereby a donor kidney is placed into a patient (recipient) with end-stage renal disease.

The donor kidney is placed on one side or the other in the lower abdomen of the recipient. Large blood vessels above the groin supply the donor kidney with blood. The diseased kidneys are not removed during the kidney transplant. Sometimes they may need to be removed prior to the kidney transplant for medical reasons. Most often, however, they are not removed.



*National Kidney and Urologic Diseases Information Clearinghouse
National Institute of Diabetes and Digestive and Kidney Diseases, NIH*

After a successful kidney transplant, the donor kidney will do the work the diseased kidneys could no longer perform. Thus, there will no longer be a need for dialysis.

Kidney donors can come from a live person, such as a family member or a close friend. Kidney donors may also come from a deceased donor. A deceased donor is someone who has recently died, whose family members have donated the deceased person's organs for transplantation. To be eligible for a deceased donor organ, you must be placed on a waiting list. Unfortunately, there are far more people in need of organs than there are deceased donor organs. Wait time varies, depending on a good match and other factors.

Tests to match your blood type and tissue type must be done to find a kidney that will most likely be accepted, not rejected, in your body. If you have a living donor relative or a friend with a different blood or tissue type from yours, however, [a new procedure](#) has made it possible to make a successful match.

Immunosuppression drugs are used to prevent or treat rejection of the new kidney. There are some side effects or complications from these drugs, but they are becoming safer and more effective.

A transplant recipient's stay in the hospital averages about a week for uncomplicated kidney transplants. Living donors can expect to stay in the hospital from three to seven days, again depending on how complicated the surgery is.

The Johns Hopkins Comprehensive Transplant Center Incompatible Kidney Transplant Programs



The Johns Hopkins Comprehensive Transplant Center's Incompatible Kidney Transplantation Program allows many patients previously thought to be "incompatible" to receive the gift of life. The program is comprised of several elements:

- Blood Type Incompatible Kidney Transplant Program
- Positive Crossmatch and Sensitized Patient Program
- Paired Kidney Exchange Program
- Altruistic Donor Program

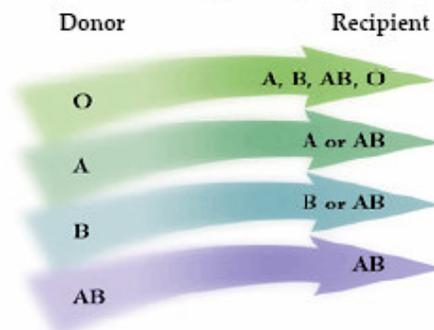
Blood Type Incompatible Kidney Transplant Program

More than one-third of willing live donors are turned down because their blood types are not compatible with the person to whom they wish to donate their kidney.

Most of us have natural antibodies against organs from people with different blood types. These antibodies can rapidly destroy a transplanted kidney.

The **Blood Type Incompatible Transplant Program** allows patients to receive a kidney from a live donor who has an incompatible blood type (see fig1.). Patients in this program must be willing to undergo all prescribed treatments before and after the transplant to remove harmful antibodies and decrease the risk of rejection.

Figure 1: *Blood Type Compatibility Chart*



How are harmful antibodies removed?

Harmful antibodies are removed with a process called plasmapheresis, a procedure similar to dialysis that removes the plasma portion of the blood where antibodies are located. The number of plasmapheresis treatments required by the recipient before surgery varies depending on the amount of harmful antibodies in their blood.

After each plasmapheresis the recipient receives an intravenous infusion of immune globulin to replace antibodies needed to fight infections and help prevent harmful antibodies from returning. Once the antibodies against the donor's blood type decrease to very low levels, the transplantation can take place.

(Blood Type Incompatible Kidney Transplant Program continued)

Do harmful antibodies return and damage the new kidney?

To prevent the antibodies from returning and damaging the kidney, the recipient has several plasmapheresis treatments and doses of immune globulin after the transplant. In addition, the recipient's spleen may be removed during the transplant procedure through tiny incisions. The spleen is the organ where antibodies are produced. (Please refer to the glossary for further explanation of the role of the spleen). A low level of antibodies may return after the transplant but does not appear to damage the new kidney.

How are antibodies detected?

After the transplant, the Hopkins team closely monitors the recipient for signs of rejection. This monitoring consists of regular clinic visits and twice weekly blood work to detect rising antibody levels, or decreasing kidney function. A kidney biopsy, in which small pieces of tissue are examined, also can detect rising antibody levels.

Recipients return to The Johns Hopkins Hospital several times during the first year after transplant to have kidney biopsies.

Does the recipient need extra immunosuppressive medication?

Normally, a kidney transplant recipient takes three immunosuppressive medications. A recipient who has received a blood type incompatible kidney transplant takes these same three medications, as well as five doses of a fourth medication. If rejection is suspected, the recipient may need additional plasmapheresis treatments and a kidney biopsy to determine if the rejection is due to antibodies coming back.

How successful are blood type incompatible kidney transplants?

At The Johns Hopkins Hospital, these transplants have been very successful and our results are comparable with those achieved with compatible transplants. Worldwide experience shows that 82 percent of blood type incompatible kidney transplants are working one year after transplant and 78 percent are functioning five years after transplant. We believe the Hopkins Protocol has features that produce better results than those achieved by others in the past.

What are the requirements for transplantation?

All transplant patients undergo a standard pre-transplant evaluation at The Johns Hopkins Hospital and must be medically and surgically cleared to receive a transplant. This will involve both laboratory and X-ray testing. Some additional blood work will be necessary for patients receiving plasmapheresis. There may be some medical conditions that will need to be treated prior to the initiation of plasmapheresis. Rarely, these conditions could exclude the patient from participation in these programs. Patients who live more than three hours driving distance from The Johns Hopkins Hospital are encouraged to stay locally for a month after the transplant.

What are the requirements for potential donors?

All donors must undergo a thorough evaluation that includes laboratory testing, X-rays and urine tests for kidney function. In addition, a nephrologist (a doctor who specializes in kidney disease), a transplant surgeon, and a psychologist evaluate potential donors. The donor receives no additional therapy. They undergo the same preparation and operation as any live donor. The donor kidney is removed using a minimally invasive technique called a laparoscopic nephrectomy that was pioneered by the Johns Hopkins transplant team in 1995.

The Johns Hopkins Comprehensive Transplant Center Incompatible Kidney Transplant Programs



Positive Crossmatch and Sensitized Patient Program

Are you Sensitized?

If you are, you are not alone. About 30 percent of patients waiting for kidney transplants are considered sensitized. Sensitized patients have developed harmful antibodies in their blood against foreign tissue. A person can develop antibodies through previous exposure to foreign tissue resulting from pregnancies, previous transplants, or blood transfusions. Sensitized patients may wait three or four times longer than unsensitized patients for a compatible cadaveric kidney.

What is a Positive Crossmatch?

The level of harmful antibody is quantified by panel reactive antibodies or PRA. A potential recipient who has a PRA greater than 30 percent is considered sensitized. Many sensitized patients have live donors willing to give them a kidney, but the transplant has little chance of success. When the recipient's blood is mixed with the donor's blood (a test called a crossmatch), the sensitized recipient's antibodies react against the donor's cells. This is called a positive crossmatch, which means the recipient probably will reject the kidney immediately following transplant. A negative crossmatch is needed between the recipient and the donor prior to the transplant.

If the antibodies in the recipient's blood can be removed prior to the transplant and be prevented from coming back, a successful live donor transplant is possible. To do this, physicians and scientists at The Johns Hopkins Hospital have developed a protocol to remove harmful antibodies from patients who have a Positive Crossmatch and are Sensitized to their live donor.

What does the treatment involve?

As in the blood type incompatible program, sensitized patients undergo plasmapheresis treatments to help remove harmful antibodies from the blood. On average, patients receive about four treatments before the transplant but the actual number required is determined by the level of harmful antibodies in the recipient's blood. An intravenous infusion of immune globulin is given after each plasmapheresis treatment to help prevent harmful antibodies from coming back after the transplant. Recipients undergo plasmapheresis and immune globulin treatments every other day starting one to two weeks prior to the transplant. For example, if the number of treatments needed is four, the recipient begins plasmapheresis eight days prior to the transplant. The recipient receives these treatments on an outpatient basis without disruption of their dialysis schedule.

Do harmful antibodies return and damage the new kidney?

After the transplant, recipients have several additional plasmapheresis treatments, followed by intravenous immune globulin, to prevent harmful antibodies from coming back. The level of antibodies in the recipient's blood is checked frequently following the transplant to determine if more plasmapheresis treatments are needed. After all the plasmapheresis treatments are completed, these patients receive the same medications as any other transplant patients.



Janet Hiller, a transplant clinical nurse specialist and Dr. Robert A. Montgomery, Director of the Incompatible Kidney Transplant Program meet with new patients and family members to discuss treatment options.

The Johns Hopkins Comprehensive Transplant Center Incompatible Kidney Transplant Programs



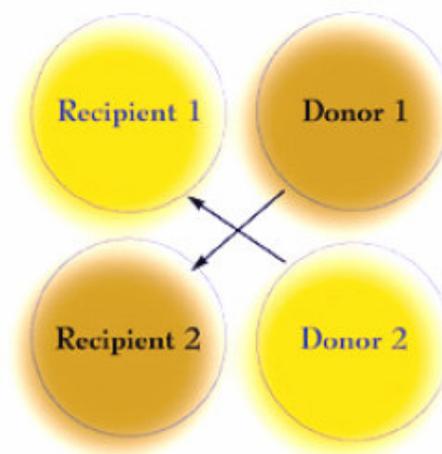
Paired Kidney Exchange Program

People with kidney failure who find a willing donor whose blood type is not compatible would need to undergo treatments described in the Blood Type Incompatible Transplant portion of this website before they can receive a kidney. However, if a donor and recipient can be found who have the opposite blood type incompatibility, kidneys can be exchanged between the two pairs and two compatible live donor transplants are possible. This is called a Paired Kidney Exchange Transplant. It can be very difficult for us to find a suitable exchange pair for certain blood types and most patients do end up having blood type incompatible transplants but, if desired, we will look for a suitable exchange pair.

How does a paired kidney exchange work?

A paired kidney exchange consists of two donor/recipient pairs whose blood types are not compatible. In the first pair, Recipient 1 is not compatible with Donor 1. In the second pair, Recipient 2 is not compatible with Donor 2. However, Donor 1 is compatible with Recipient 2 and Donor 2 is compatible with Recipient 1. If you and your donor are willing to “exchange,” you are matched with another donor/recipient pair.

Paired Kidney Exchange Chart



Once the evaluations of all donors and recipients are completed, the transplant is scheduled. The two kidney transplants occur on the same day. The two donor and recipient operations occur simultaneously.

Can Donors and Recipients Meet?

It is possible for the donors and recipients to meet or contact each other after the transplants. This is arranged by the transplant coordinator and must be agreed upon by both donor and recipient pairs.

The Johns Hopkins Comprehensive Transplant Center Incompatible Kidney Transplant Programs

Altruistic Donor Program

In September of 1999, a transplant coordinator from the Midwest named Joyce Roush became the first known person to donate a kidney to a stranger. She and the child who received her kidney underwent the successful procedure at The Johns Hopkins Hospital. Her gift inspired many others to follow in her footsteps prompting us to initiate the Altruistic Donor Program, which matches willing donors with our most needy recipients. Because kidney disease prevents children from growing properly they are given preference for these kidneys. John Temple, a United States Air Force retiree, read an article in the Indianapolis Star about Joyce Roush and was himself inspired to donate a kidney. A child unknown to him was given the gift of life as a result of his kindness.

"I knew little about the operation or kidney disease in general," says Temple. "[But] I knew people were dying every day [who] could be saved if additional kidney donors could be found. Becoming a living kidney donor is a serious decision, with some risks, but many rewards. I couldn't get past the idea that the slim chance that this surgery might affect my quality of life was more than offset by the knowledge that my kidney might mean all the difference to some child who would have no life at all if I backed away."

What can an anonymous donor expect?

Over the next 15 months Mr. Temple had two intensive days of screening in Baltimore, numerous blood tests—often with little notice, several potential candidates that didn't work out, and a great deal of patience. The process can be frustrating for anonymous donors because there is no emotional connection with a specific patient over the months of waiting.

Temple's wait ended when his kidney was transplanted on a Friday in early November 2000. He was able to leave the hospital Sunday afternoon, and within three weeks he was "almost 100 percent." With the new kidney, the recipient, a young boy named Ryan whom Temple later met, was able to discontinue dialysis and lead a normal life.

"Once I really understood all he [Ryan] faced, it put my poor sacrifice to shame. It also convinced me ...to become a more vocal advocate of anonymous organ donation," says Temple. "Despite the obstacles, I consider it one of the best decisions of my life."

What are the benefits of live kidney donation?

- Recipients receive a live donor kidney transplant and an enhanced quality of life.
- A live donor kidney lasts about twice as long as a cadaveric kidney on average.
- A willing donor is able to fulfill the wish to donate.
- The gap between patients waiting and kidneys available for transplantation is closed.
- A deceased donor kidney is made available for someone who has no live donor.
- The benefits double for paired kidney exchanges as two people receive live kidney donations.

The Johns Hopkins Comprehensive Transplant Center Incompatible Kidney Transplant Programs



Glossary

Antibodies: a protein that is part of the body's immune system. Antibodies are produced in response to foreign tissues. Some antibodies are harmful to transplant patients and can cause them to reject organs they are "sensitized" to or incompatible with.

Crossmatch: the mixing of blood between donor and recipient to detect harmful antibodies.

Immune Globulin: an intravenous medication which help protect the body from disease and prevents harmful antibodies from returning.

Immunosuppressive medications: medications used to suppress the recipient's immune system and prevent rejection of the transplant.

Kidney biopsy: a procedure in which a needle is used to obtain small pieces of tissue from the kidney for examination under a microscope.

Plasmapheresis: a procedure in which the plasma portion of the blood is removed along with harmful antibodies and replaced with a plasma-like substance.

PRA (panel reactive antibodies): a gauge to measure the amount of antibodies in the recipient. The higher the PRA, the more difficult it is to find a compatible organ for transplant.

Spleen: a soft, spongy purplish organ that houses cells that produce antibodies. In adulthood, the spleen is less important but does continue to play a role in filtering the blood of certain bacteria. Patients who have had their spleen removed are immunized to protect them from bacteria.

From the Director

The critical shortage of deceased donor kidneys for transplantation is not expected to change in the near future; in fact, each day the gap between available kidneys and the number of patients waiting for a transplant widens. The only real hope to close this gap is utilization of live donors.

Physicians and researchers at Johns Hopkins continually develop new ways to increase the number of patients who receive kidneys from live donors. In 1995, Johns Hopkins surgeons developed a new procedure called the laparoscopic donor nephrectomy which makes donating easier because the kidney is removed through small incisions. Since the advent of this procedure we have seen a sharp rise in the number of people willing to donate a kidney. Live kidney donations not only help critically-ill patients, they tend to last twice as long as cadaveric transplants and they free up deceased donor organs for others on the waiting list who have no eligible live donors.

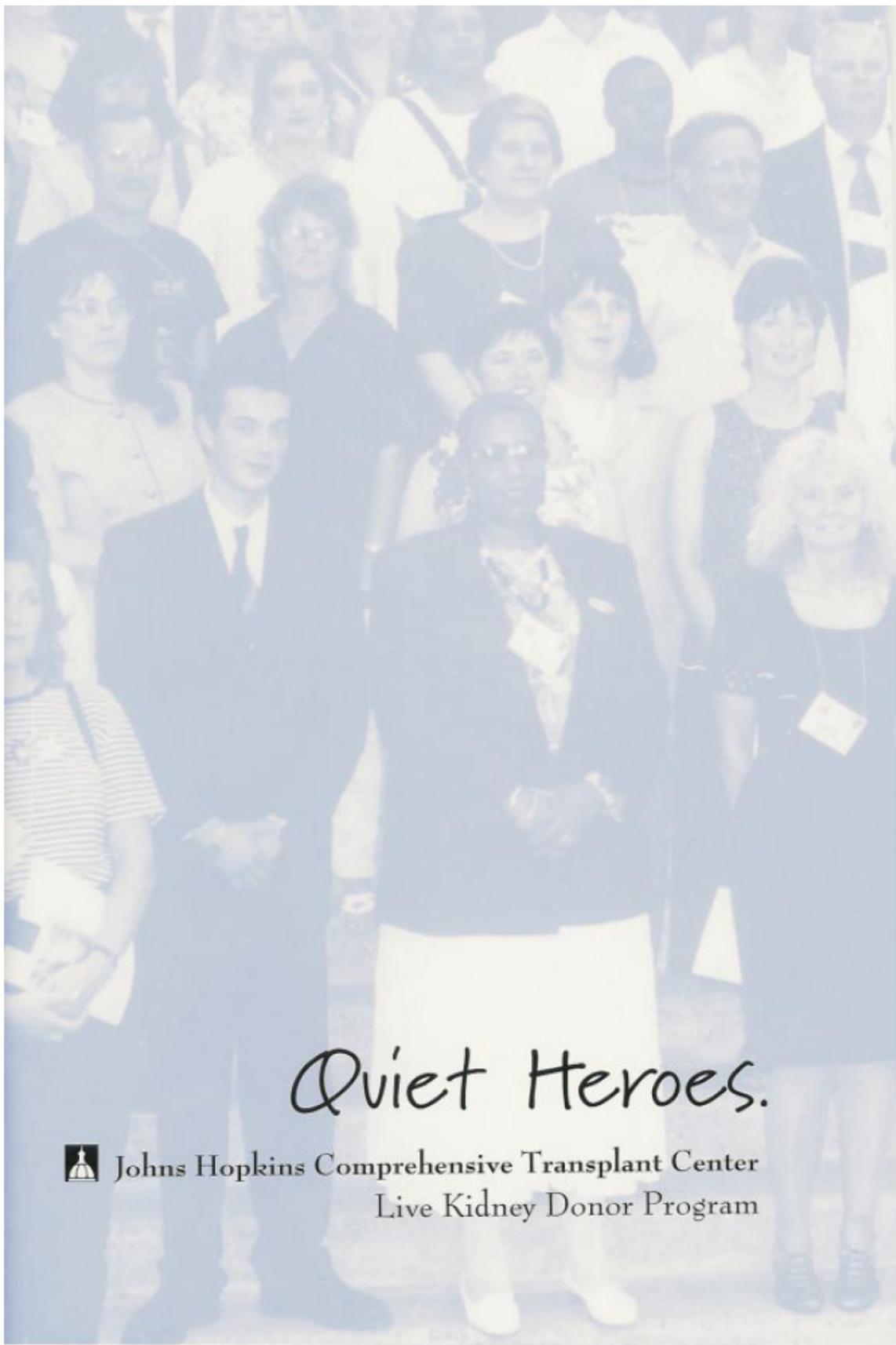
The transplant team at Hopkins has pioneered several new innovations that now make it possible for any patient with renal failure to receive a kidney from any donor, regardless of their blood or tissue type.

The Blood Type Incompatible, Positive Crossmatch/Sensitized Patient, and Paired Kidney Exchange Programs will allow many patients previously thought to be "untransplantable" to receive the gift of life. The Altruistic Donor Program makes kidneys from anonymous live donors available to patients, usually children, who are disproportionately disadvantaged on the waiting list.

Robert A. Montgomery, M.D., D.Phil.
Director, Incompatible Kidney Transplant Program

The Johns Hopkins Comprehensive Transplant Center Incompatible Kidney Transplant Programs





Quiet Heroes.



Johns Hopkins Comprehensive Transplant Center
Live Kidney Donor Program

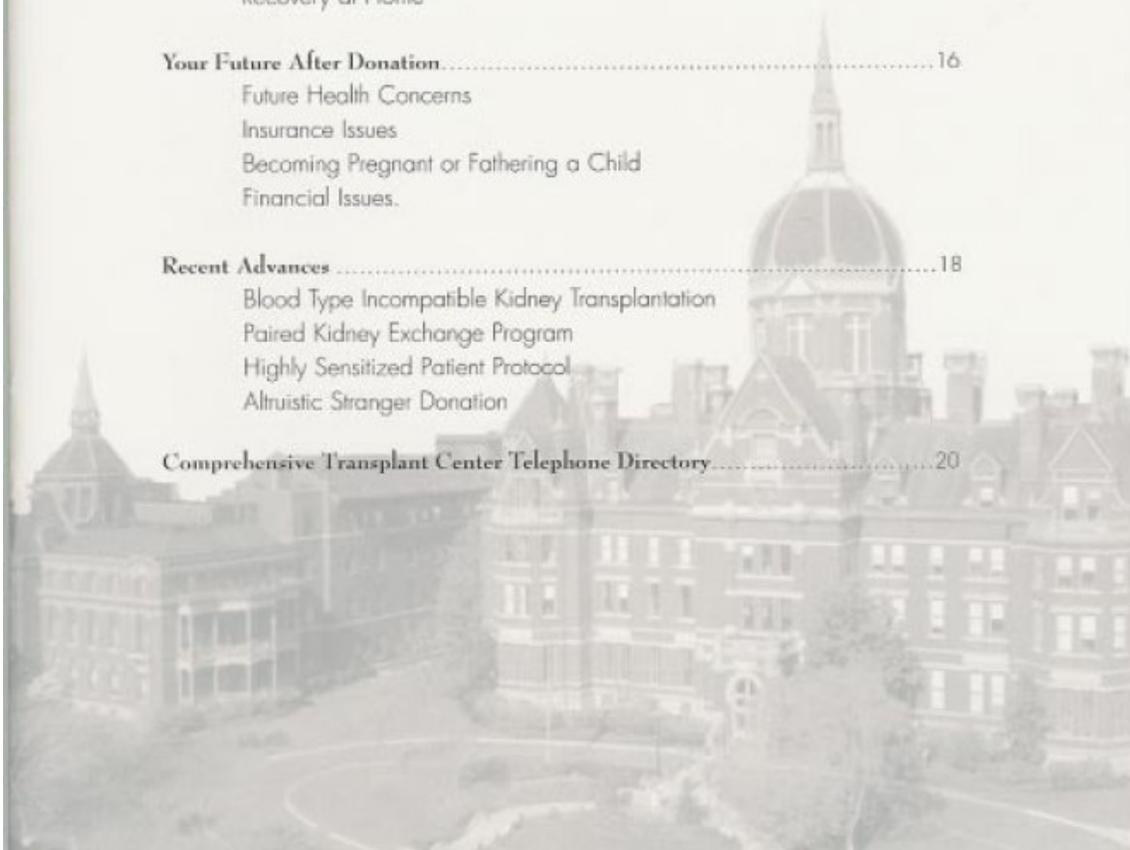
Donor.

A giver, a contributor,
a supporter, a benefactor,
a selfless humanitarian,

A hero.

Introduction

Advantages to Live Donor Kidney Transplants	6
Choosing to be a Live Donor	8
Who can be a live donor	
Concerns of live donors	
Safety of donor surgery	
Benefits of being a live donor	
The Donor Evaluation	10
Blood and Tissue Type matching	
Initial Screening Tests	
One – Day Donor Evaluation	
Scheduling the Donor Surgery	
Transplant Day	13
The Donor Surgery	
Initial Recovery in the Hospital	
Recovery at Home	
Your Future After Donation	16
Future Health Concerns	
Insurance Issues	
Becoming Pregnant or Fathering a Child	
Financial Issues.	
Recent Advances	18
Blood Type Incompatible Kidney Transplantation	
Paired Kidney Exchange Program	
Highly Sensitized Patient Protocol	
Altruistic Stranger Donation	
Comprehensive Transplant Center Telephone Directory	20



Quiet heroes.

At Johns Hopkins Hospital, we're privileged to see heroes everyday. The quiet heroes. The people who save others—related, unrelated, even total strangers—with a living organ donation.

This booklet describes the live kidney donor program at the Johns Hopkins Hospital Comprehensive Transplant Center.

For over 40 years, Johns Hopkins has performed hundreds of live donor kidney transplants. Unfortunately, though, the number of people waiting for a transplant far exceeds the number of donors.

Until recently, it wasn't easy to be a live donor. First you had to be related to the recipient, then your blood and tissue type had to be compatible. Also the donor surgery discouraged some people from donating because it resulted in a large scar, substantial pain and a prolonged period of recovery. These obstacles eliminated up to 35% of the people who wished to donate. Today, thanks to innovative surgical techniques and pioneering research, most of the people who wish to donate are now able to do so.

In 1995, surgeons Lloyd Ratner, MD and Robert Montgomery, MD and urologist Louis Kavoussi, MD developed the new live donor surgical procedure called the laparoscopic nephrectomy. Unlike the older method that removed the kidney through a large incision, the laparoscopic nephrectomy uses only four small incisions. The results are amazing. Donors now have shorter recovery time and much less pain. Over 400 laparoscopic live donor nephrectomies have taken place at Hopkins. Surgeons from all over the world travel here to learn this procedure.



"Donating to my son was the most wonderful thing I've ever experienced in my life. It was like giving birth again."

PATRICE ERVIN, KIDNEY DONOR
TO HER SON ANDREW





*"I'm so thankful I was available as a donor...
This was such a positive experience."*

JAMES BAILY, III, KIDNEY DONOR TO HIS DAUGHTER, BELINDA

Even with the new surgical procedure, donors were still being turned down because they weren't blood-type or tissue compatible with their recipients. Today, Johns Hopkins is able to offer three exciting live donor programs that safely allows incompatible donors to donate their kidneys. For donors and recipients whose blood types do not match, you may be eligible to participate in a **Blood-Type Incompatible Transplant** or in a **Live Donor Paired Kidney Exchange (Donor Swap) Transplant**.

Perhaps the donor and recipient have been told their tissue is not compatible. This is common when a recipient has had a previous transplant, blood transfusions or pregnancies. The recipient becomes sensitized to the donor. The **Highly Sensitized Patient Transplant Program** is designed to desensitize the recipient through a special treatment called plasmapheresis so a successful live donor transplant can then take place.

All three of these novel programs have been highly successful. You'll find more information about these programs later in the booklet. Now, more than ever, almost anyone who is medically eligible can be a live kidney donor.

There are heroes out there. Quiet ones willing to perform a selfless act of courage, to save a life. At Hopkins, we are dedicated to fulfilling the wish of donors to give the gift of life.



Advantages to Live Donor Kidney Transplants

No medals. No ticker tape
parades. Just the everlasting
thanks of another human
being.

There are many advantages to live donor kidney transplants, starting with the fact that it may be the recipient's only hope.

When people have End Stage Renal Disease (ESRD), they don't have many options. They can rely on a dialysis machine to remove waste products from their blood, and they can have their name placed on the waiting list that is maintained by the United Network for Organ Sharing (UNOS) for a kidney transplant.

Dialysis is time-consuming and limits a person's family and work life. Consequently, kidney transplantation, with its well documented, high rate of success, is the preferred option for most patients.

There are over 50,000 people on the UNOS list waiting for a kidney today. Only 10,000 cadaveric kidneys become available every year. Thus the wait for a cadaveric kidney can take up to four years or more. Obviously, cadaveric donation alone can not ease the shortage.

Thanks to newer surgical techniques, the number of people interested in live kidney donation has been increasing. That's very good news. There are many advantages to a live donor kidney transplant.

Unlike a cadaveric transplant, the live donor transplant can be planned ahead of time, when the recipient is in better health. The kidney can be transplanted minutes after being removed from the donor instead of hours as is the case with cadaveric donation. Most important of all, the long-term survival rates of live donor transplants are much higher.



Receiving a live donor transplant may also allow a patient to avoid dialysis altogether if the transplant is done when the kidney failure is first found.

There is one more, very important advantage to live donation—using a live donor organ frees up a precious cadaveric kidney for someone else who doesn't have a live donor.

The following pages will answer some of the questions asked most often about live kidney donation. We're sure you'll have some of your own. Specially trained members of the transplant team are ready to answer any questions you may have. You'll find their telephone numbers at the end of the booklet.

TRANSPLANT RECIPIENTS AND MEMBERS DAVID JENKINS (LEFT)
AND MICHAEL COONFIELD (RIGHT) OF TEAM MARYLAND,
UNITED STATES TRANSPLANT OLYMPICS



Choosing to be a Live Donor

The greatest gift.

Who can donate?

In the past, only people related to the recipient could be a donor. Now, living donors can be friends, in-laws, neighbors, co-workers, fellow church members, even complete strangers.

You only have to be healthy, willing to donate and at least 18 years of age. There are, however, certain medical problems that would make you ineligible, such as a history of high blood pressure, cancer, diabetes, kidney or heart disease.

What are some concerns donors have before deciding to donate a kidney?

Many donors are so comfortable with their decision, they have no concerns, but almost everyone has questions about the donation process. How much discomfort is associated with the surgery? How long will it take to get better? How much time will it take away from work? Will the donor incur any cost? Some donors express fear. Some even feel guilt about being afraid. Whatever concerns you have, the transplant team is available to help you get the answers you need. Your decision must be the right decision for you.



"Allegra, I am going to donate my kidney to you... I see her doing all the things she did before. She is my hero."

ED WILLIAMS, KIDNEY DONOR
TO HIS DAUGHTER, ALLEGRA



How safe is the donor surgery?

While the laparoscopic technique has made the operation easier for the donor, it is still major surgery. As with any operation, you will have pain and discomfort. There is also a risk of bleeding and infection. But these problems will be fully discussed before you consent to the operation. The chance of death for living donation is 0.06 percent or 6 in 10,000 donors.

What are the benefits of being a donor?

Only someone who has been a donor can truly answer. Here's what some of them have to say:

"Donating a kidney was a revelation - I learned much more about kidney disease. This experience was spiritually uplifting and quite an emotional boost knowing I made a very tangible difference in someone's life."

JOHN TEMPLE: ALTRUISTIC DONOR

"The benefit of donating a kidney was knowing that I could help Bob return to his normal life which includes dentistry and travel. Our family was able to get back to normal and Bob's patients were thrilled to have him back. I also benefitted by knowing that I did the right thing spiritually. I feel I answered to the call of God just as I did when I went to the seminary."

TOM PARKER: DONATED A KIDNEY TO HIS BROTHER BOB

"It was such an uncertain and frightening time when we first learned that Belinda would have to be on dialysis and need a kidney transplant. My decision to volunteer was an easy one, especially after the procedure and benefits to the recipient were explained. I am so thankful that I was available as a donor...This was such a positive experience."

JAMES BAILEY, III: KIDNEY DONOR TO HIS DAUGHTER, BELINDA



The Donor Evaluation

There's only one rule:
Nothing is more
important than
your health.

Once you have decided to become a donor, you will meet with a transplant nurse coordinator to plan your evaluation. Your health is our number one concern. A thorough medical exam will be scheduled to make sure you are healthy enough to be a donor.

Donor evaluation is divided into four phases:

- Blood and Tissue Type Matching.
- Initial Screening Tests.
- One-Day Donor Evaluation.
- Scheduling the Donor Surgery.

Blood and Tissue Type Matching.

You will have blood drawn to see if you and the recipient have compatible blood types and to check the degree of your genetic matching in what is called a Human Leucocyte Antigens (HLA) test. If your blood type is not compatible with the recipient, it may still be possible for you to donate your kidney. Information about Blood Type Incompatible (ABOI) Transplants is covered later in this booklet. See Table 1 for compatible blood types.

We use the HLA test to predict the likelihood of your kidney being rejected by the recipient. We mix, or crossmatch, both of your blood cells. If the recipient's cells "kill" your donor cells, the crossmatch is positive. If not, it's negative. A negative crossmatch means it's highly unlikely that your kidney will be rejected. A positive crossmatch means that it probably will be.





"Our family was able to get back to normal and Bob's patients were thrilled to have him back. I also benefitted by knowing that I did the right thing spiritually."

TOM PARKER (LEFT): KIDNEY DONOR TO HIS BROTHER, BOB

In the past, when a positive crossmatch occurred, you could not donate. Today, an exciting new advance in immunology can often eliminate positive crossmatches. This **Highly Sensitized Patient Protocol** is described in more detail later in the book.

Table 1: Compatible Blood Types for Organ Donation

If the DONOR is —————> The RECIPIENT can be

Blood Type O	Blood Type A, B, AB, O
Blood Type A	Blood Type A or AB
Blood Type B	Blood Type B or AB
Blood Type AB	Blood Type AB



Initial Screening Tests.

During initial screening, blood work and urine tests will be done. You'll collect a 24-hour urine specimen that will show how well your kidneys are working. Your blood will be checked to see what viruses you have been exposed to in the past. Women must also provide the results of a current pap smear and mammogram. More tests may be added based on the results of this initial screening. If you don't live close to Johns Hopkins Hospital, these tests can be done in your hometown.

One-Day Donor Evaluation.

If no problems are found, a One-Day Donor Evaluation is set up at Johns Hopkins Hospital. You'll meet with the Transplant Nephrologist, the Transplant Surgeon and a Psychologist. You'll also have a chest xray, an EKG and a 3 Dimensional CT Scan of your kidneys.

This evaluation takes the entire day, so if your traveling distance is greater than 3-hours, we suggest you come to Baltimore the night before. Ask your transplant coordinator for a housing and hotel list.

Scheduling the Donor Surgery.

The Transplant Committee will review the results of your tests. If your evaluation shows you would be a good donor and you wish to proceed, a surgical date will be set in preparation for the transplant.

In most circumstances, the transplant is scheduled four to six weeks in advance. This allows you to arrange time away from work, childcare, school schedules, and other daily responsibilities. This wait also gives the recipient's health time to stabilize.

If you are from out of town, our housing coordinator will help you find a place to stay in Baltimore. Donors are usually in the hospital for three days after their surgery. Donors should plan to stay in town for one week after discharge.

One week before your surgery, a visit is scheduled for both the donor and recipient at our Pre-Operative Evaluation Center. A final crossmatch will be done to make sure your tissue is still compatible.



Transplant Day

*And for the recipient,
a new birthday.*

On the day of your surgery, you will report to the Same Day Surgical Unit. The surgical nurses will take your blood pressure, heart rate and temperature. Your past medical history will be reviewed and an IV started. You'll meet your surgeon and the anesthesiologist who will care for you during your operation. You'll have plenty of time to ask any last minute questions. Finally, you'll sign the consent form, and get ready to give the greatest gift.

Donor Surgery.

Your surgery is called a Donor Nephrectomy and takes approximately four hours. Don't be surprised if you're asked to walk into the operating room. This is quite normal for healthy people who are about to undergo surgery.

The anesthesiologist will give you medicine to help you fall asleep. You will be under general anesthesia and asleep during the entire surgery. Once you are asleep, a tube will be placed into your mouth to help you breathe and a urinary catheter will be placed into your bladder to collect urine. During the surgery, you will receive 6 to 10 liters of IV fluids to keep your kidneys working well.

Most often, your left kidney is removed. Your surgeon makes three small incisions about one-half inch long, in your abdominal area. (See diagram 1). Through one incision, your abdomen is inflated with carbon dioxide to make it easier to see the kidney. Through the other incision, a tiny camera and small surgical tools are placed. The kidney will be removed through the fourth incision approximately 3 inches below your belly button.

Diagram 1:



While all this is happening, the recipient is being prepared in another operating room. When the recipient's surgeon reports that everything is ready, your kidney will be removed.

Initial Recovery In the Hospital.

You will awake in the recovery room, but you will still feel sleepy. You might also feel a little nauseous. That's normal and due to the anesthesia. Once you are stable, you will be taken to your hospital room.

Your breathing tube will be removed while you are still in the operating room, but the urinary catheter and IV will remain in place for one day after surgery. You can expect to feel puffy from all the fluid you were given during surgery. You will have gained a little weight, because each liter of fluid is equal to 2.2 pounds. Don't panic, you'll return to your normal weight in just a few days.

Pain medication is available through an IV or an injection. On the second day after surgery, or once you can tolerate food, you will be given pills to control your pain. You may also have some pain in your shoulders from the gas used to inflate your abdomen.

Soon after surgery, you'll receive a regular diet. You'll also be urged to get out of bed. Walking leads to faster recovery and helps prevent infections and blood clots in your legs. By the second post-operative day, if there are no problems, you will be able to be discharged from the hospital.

Recovery At Home.

You will experience some abdominal pain. This pain should be easily relieved with either a prescribed medication or over the counter pain relievers. In fact, most donors report they no longer need any medication three weeks or even sooner after surgery.

We recommend that you don't drive for two weeks, and don't lift anything heavier than 20 pounds for six weeks. You are encouraged to walk several times a day, both for exercise and to hasten recovery. If you have child care responsibilities, you'll need some assistance during the first week. You can expect to return to work after three or four weeks. It is common for many donors to feel easily fatigued for up to two months after surgery.



You can also expect to feel a variety of emotions from elation to a slight "let down". This is completely normal. You have just experienced an intense emotional and physical event. Be patient with yourself and your progress. Recovery and healing take time.

A post-operative visit with your surgeon will be scheduled for the following month, however, if you want to talk sooner, don't feel like you have to tough it out. You're already a hero. Your transplant team is there to help you, even after the donation.

*"I receive the best present
in the world each and
every day when my son
comes down the stairs,
healthy and energetic. At
the end of each day, I have
received a far greater gift
than I gave."*

DENNIS BONETTI: KIDNEY DONOR
TO HIS SON MATTHEW



Your Future After Donation

Turns out, what you give up is very little, about the size of a kidney.

Make no mistake, donating a kidney is no small step. You have to wonder how this is going to affect your health, your future, your life. Here are the answers to the questions we hear the most.

Will I be able to live a normal, healthy life after donating a kidney?

Absolutely. Years of research and follow up studies with live kidney donors confirm that donating a kidney does not have an adverse effect on future health in any way. It won't shorten your life, or change it, for that matter. Donors lead active lives with only one kidney. They drive, work, exercise, serve in the military, in short, do just about everything they did before. After your initial recovery, we recommend a yearly routine physical by your family physician.

Will I be able to get insurance afterwards?

A national study of insurance carriers found donors had very few problems getting insurance. Only 4 percent had difficulty getting health and life insurance. And only 2 percent had problems getting disability insurance. On *rare* occasion, donors may be asked to wait from one to three years after donation before being issued a policy. If you have difficulty with insurance, please talk to the transplant office and we will help you with this matter.

Can I have children?

According to research, there is no reason to believe that donating a kidney will affect your ability to become pregnant or father a child. In fact, the data shows almost everyone who tried to have children after donation was successful.



What costs will the donor incur?

All bills from the donor evaluation, surgery and post-operative follow-up care are taken care of by the recipient's insurance. Some costs that are not covered by private insurance or Medicare include travel costs, lost wages, childcare and daily living expenses. That's why it is important that you discuss all of your financial questions with your transplant coordinator before the donation process.



"I am happy to have given the gift of life. I am able to see the results of this gift for an ongoing period of time."

JEFF HOBSON: KIDNEY DONOR TO HIS SISTER, MARY CAPPS



Recent Advances

Johns Hopkins is leading the way in innovative strategies for helping people with end stage renal disease receive a kidney transplant. Through the recent advances described in this section, patients who, previously, had little hope of receiving a live donor kidney transplant and faced long waiting times for a cadaveric kidney can now be offered four promising opportunities for transplant.

Blood Type Incompatible Transplant Program.

Now even people with an incompatible blood type with the recipient can donate their kidney. The evaluation and surgery for the donor are just as we explained earlier, but to prevent immediate rejection of the kidney, the recipient's blood must have antibodies to the donor blood-type removed. This is done before the transplant with a process called plasmapheresis. Plasmapheresis removes antibodies from the recipient's blood that would be harmful to the donor kidney. To keep the antibodies from reforming, the recipient's spleen is removed at the time of the transplant. This is important because the spleen is the site where most of the antibody is produced. The patient receives several plasmapheresis treatments post-surgery. Once at home, the patients use the same anti-rejection medications used for all kidney recipients. Recipients who received blood-type incompatible transplants over the past two years are experiencing normal kidney function.



"No one knows how lucky I am. I'm going to get to see Lindsay start kindergarten soon and go to her high school prom. I don't need any thank you. I get to see "thank you" every time I see Lindsay."

BARBARA SIMMS, KIDNEY DONOR TO LINDSAY, THE DAUGHTER OF A CLOSE FRIEND



Paired Kidney Exchange Program.

This is an exciting new program funded by one of our patients to match blood-type incompatible donors and recipients. For example, a husband needs a kidney and his wife wants to donate, but their blood types are not compatible. Their names are put into a database and their blood types are matched with another living donor and recipient whose blood types are also not compatible. It sounds complicated, but it's really quite simple. (See illustration). Now two people who faced a long wait for a cadaver kidney can receive a live donor kidney transplant instead.



If you know your blood type is incompatible with your recipient, you'll want to find out more about these two new programs. Just call the transplant office at the number listed at the end of this booklet.

Highly Sensitized Patient Protocol.

People who have had a previous transplant, pregnancy or blood transfusion develop antibodies in their blood that won't force an immediate rejection of the transplanted kidney, but will cause one sometime after the transplant. These patients are called "highly sensitized". These patients wait a very long time for a cadaveric kidney. Many highly sensitized patients have live donors willing to give them a kidney. However, when the recipient's blood is mixed with the donor's blood, the highly sensitized recipient's antibodies act to kill the donor's cells.

Through the Highly Sensitized Patient Protocol, the recipient's blood can be cleansed of these antibodies with plasmapheresis. A successful live donor transplant is then possible. The long-term survival of the transplanted kidney is identical to that of a recipient who is not highly sensitized.

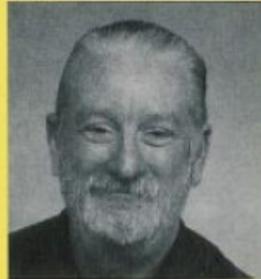


Altruistic Stranger Donation.

It's one thing to offer a kidney to someone you love, but imagine giving it to someone you don't even know. That's exactly what one transplant nurse did in 1998, when Johns Hopkins Hospital performed its first altruistic donor kidney transplant.

This nurse wanted to show the world that being a live donor was a safe and rewarding way to help the thousands of patients waiting for a kidney. And did she ever! Since her donation, over 100 people from 26 different states have expressed interest in Altruistic Kidney Donation. A total of six altruistic kidney donor transplants have taken place since the first one in 1998. All from just one selfless act.

If you're thinking of being a live kidney donor, we hope this booklet has given you the basic information you need. As always, the Johns Hopkins Hospital Comprehensive Transplant Center is ready to answer any of your questions.



*"I made a very tangible difference
in someone's life."*

JOHN TEMPLE: ALTRUISTIC STRANGER DONOR



Comprehensive Transplant Center Telephone Directory

Johns Hopkins Hospital

Main Number:
410-955-5000

Abdominal Transplant Office

Toll-free:
1-888-304-5069, choose Option #3.
Follow prompts to appropriate office.

Direct office lines:
410-955-5045

Fax number:
410-614-8694

Transplant Patient Support and Outreach Office

410-614-5700

Transplant Insurance Coordinator Office:

410-955-5224

Dedication:

We would like to dedicate this book
to the courageous men and
women who steadfastly devote their
lives to the care and protection
of their fellow human beings.
A hero each and every one....



*Front Cover: Johns Hopkins Comprehensive
Transplant Center organ donors.*

*Back Cover: Johns Hopkins Comprehensive
Transplant Center organ recipients.*



Johns Hopkins Comprehensive Transplant Center

600 N. Wolfe Street, Osler 603

Baltimore, Maryland

21287



ABDOMINAL TRANSPLANTATION
Physicians' Listing

The University of Maryland Medical Center's Division of Transplantation is a comprehensive program offering kidney, pancreas, simultaneous kidney-pancreas, liver, simultaneous liver-kidney and islet cell transplants. Round-the-clock access to our physicians and services is available through *OneCall* at **1-800-373-4111**.

TRANSPLANT SURGEONS

Benjamin Philosophe, M.D., Ph.D.
 Head, Division of Transplantation
 Director, Liver Transplantation
 Associate Professor of Surgery
 410-328-1145
 bphilosophe@smail.umaryland.edu

Stephen T. Bartlett, M.D.
 Barbara Baur Professor & Chair,
 Department of Surgery
 410-328-8407
 sbartlett@smail.umaryland.edu

Eugene J. Schweitzer, M.D.
 Surgical Director, Renal Transplantation
 Professor of Surgery
 410-328-8416
 eschweitzer@smail.umaryland.edu

Matthew Cooper, M.D.
 Director, Clinical Research
 Associate Professor of Surgery
 410-328-7336
 mcooper@smail.umaryland.edu

Luis Campos, M.D.
 Assistant Professor of Surgery
 410-328-2691
 lcampos@smail.umaryland.edu

David B. Leaser, M.D.
 Clinical Director, Islet Cell Transplantation
 Instructor, Department of Surgery
 410-328-5408
 dleaser@smail.umaryland.edu

TRANSPLANT NEPHROLOGISTS

Matthew R. Weir, M.D.
 Chief, Division of Nephrology
 Professor of Medicine
 410-328-5730
 mweir@medicine.umaryland.edu

David Klassen, M.D.
 Professor of Medicine
 410-328-5720
 dklassen@medicine.umaryland.edu

Chuck Cangro, M.D., Ph.D.
 Medical Director, Post Transplant
 Assistant Professor of Surgery
 410-328-5720
 ccangro@medicine.umaryland.edu

TRANSPLANT HEPATOLOGISTS

Jacqueline Laurin, M.D.
 Clinical Director, Hepatology
 Associate Professor of Medicine
 410-328-5196
 jlaurin@medicine.umaryland.edu

Charles D. Howell, M.D.
 Associate Professor of Medicine
 410-328-5196
 chowell@medicine.umaryland.edu

NURSE COORDINATORS

Clinical Nurse Manager for Liver/Kidney/Pancreas
 410-328-9154

Liver Transplant Nurse Coordinators
 410-328-3444

Living Kidney Donor Coordinators
 410-328-5408

Pre-Transplant Kidney/Pancreas Coordinators
 410-328-5408

Post-Transplant Kidney/Pancreas Coordinators
 410-328-3616





INFORMATION ABOUT

LIVING KIDNEY DONATION

UNIVERSITY OF MARYLAND MEDICAL CENTER DIVISION OF TRANSPLANTATION

WHAT KIDNEY PATIENTS NEED TO KNOW

A living donor kidney transplant is a treatment option for patients with End Stage Renal Disease (ESRD). ESRD occurs when patients have lost most or all of their kidney function. Other treatment options for patients with ESRD are dialysis or a kidney transplant from a deceased organ donor.

This information sheet is intended to help educate kidney patients about living kidney donation. It is helpful for kidney patients to know some facts about living donation so that they can share accurate information with family and friends who may be interested in donating a kidney.

BENEFITS OF A LIVING DONOR TRANSPLANT

- Eliminates the long wait time for kidney patients on the national waiting list for deceased donor organs.
- Allows the surgery to be scheduled at a convenient time for both the donor and the recipient.
- Enables more time for surgical preparation.
- Improves outcome for kidney recipients, including a shorter recovery time and increased survival of the transplanted kidney, compared to deceased donor organs.

QUALIFICATIONS FOR LIVING DONORS*

- Donors must be in good physical and psychological health.
- Must be free from diabetes, cancer, and kidney, heart, liver, and lung disease, as well as free from HIV and hepatitis.
- Persons with high blood pressure must meet specific criteria.
- Must be at least 18 years old.
- Gender, race, similar age and family relation are not factors in determining a successful match.

* This list provides an overview of general qualifications. Donors must complete a comprehensive evaluation prior to donation.

– More Information on Other Side

www.um.m.edu/transplant

 UNIVERSITY OF MARYLAND
MEDICAL CENTER



INFORMATION ABOUT

LIVING KIDNEY DONATION

UNIVERSITY OF MARYLAND MEDICAL CENTER DIVISION OF TRANSPLANTATION



TESTING

- Initial blood testing is performed on the donor to determine compatibility with recipient.
- If the donor and recipient have compatible blood types, the donor will then undergo medical and psychosocial evaluations and further testing.

RISKS OF LIVING DONATION*

- Most risks of donation are similar to any major surgery but are very rare: infections and bleeding.
- Death resulting from kidney donation is rare.
- Donating a kidney does not change life expectancy.
- Donation does not increase the risk of developing kidney disease.
- Kidney donation does not put donors at a higher risk for health problems when compared to general population.
- Kidney donation should not affect the ability to have or maintain medical and life insurance, though, donors should confirm this with their insurance providers.

SURGERY AND HOSPITAL STAY

- Laparoscopic surgery is the technique most commonly used for kidney donation.
- This minimally-invasive operation is performed through a series of small incisions.
- Hospital stay for donors is usually 2-3 days.

QUALITY OF LIFE AFTER KIDNEY DONATION

- Most donors return to their jobs within 2-3 weeks (sometimes longer depending on the physical demands of job).
- A person can lead an active and normal life with a single kidney.
- After recovery, a donor can drive, exercise, and participate in sports and other physical activities.
- A donor can continue in all types of occupations, including military duty.
- Being a donor does not impact a person's ability to have a child.

DISCUSSING LIVING DONATION WITH FAMILY AND FRIENDS

Many family members and friends are eager to help someone in need of a kidney, but they do not know the facts about kidney donation.

- A patient can share information about living donation with their loved one and allow them the opportunity to ask questions and seek additional information.
- Individuals should not be pressured to donate.
- When interested donors are provided with correct information about donation, many will choose to proceed with testing.

For more information on living kidney donation at the University of Maryland Medical Center, please go to the website: www.umm.edu/transplant.

You may also call a Nurse Coordinator from the **Living Donor Kidney Program** at (410) 328-5408.

** This list provides an overview of the risks. The donor will discuss risks in detail with the transplant team.*



QUESTIONS AND ANSWERS
to becoming a Living Donor

KIDNEY TRANSPLANTATION

LAPAROSCOPIC KIDNEY DONATION



THE DIVISION OF
TRANSPLANTATION
AT THE UNIVERSITY
OF MARYLAND
MEDICAL CENTER

 UNIVERSITY OF MARYLAND
MEDICAL CENTER

MAKING THE DECISION

Becoming a living donor is a major decision, but due to the ongoing shortage of cadaver kidneys, the number of living kidney donations is increasing each year.

Many people are now opting to give the gift of life by donating a kidney to a relative, friend, church member or co-worker in need.

This brochure is designed to help the donor, the donor's family, and the recipient understand a living kidney donor transplant.

HOW DO FAMILY AND FRIENDS KNOW WHEN IT IS TIME TO CONSIDER KIDNEY DONATION?

When a patient loses 90 to 95 percent of his or her kidney function, life-saving treatment becomes necessary. Treatment options are dialysis: an artificial kidney machine removes wastes from the blood, or a kidney transplant from a living or deceased donor.

Sometimes, a patient with an 85 percent loss of kidney function will undergo a transplant which allows a person to avoid dialysis.

WHO CAN BE A DONOR?

Donors can include parents, children, and siblings, as well as distant relatives, friends, church members, co-workers, etc. The donor and the recipient need to have compatible blood types, and all donors must be willing and healthy. A donor needs to be between the ages of 18 and early 70's.

It is important that donors understand what the procedure involves: testing, surgery, recovery period and possible risks.

Typically, someone who has high blood pressure (both treated and untreated), cancer, diabetes, kidney disease, heart disease, liver disease or sickle cell disease will not qualify to be a donor. These are not all absolute contradictions to donation. Every donor will be evaluated on an individual basis.

WHAT IS THE FIRST STEP?

When someone decides to be considered as a donor, he or she will undergo two blood tests to determine blood type and tissue type. If the donor candidate's blood type is compatible with the recipient, then the transplant team will discuss the entire donation process with the donor so he or she can make an informed decision. If the donor candidate decides to donate a kidney, then the medical evaluation begins.

WHAT DOES THE MEDICAL EVALUATION INCLUDE?

The HLA tissue typing, often referred to as "matching," determines how well the donor matches with the recipient. A donor's blood cells are mixed with the serum from the recipient in a "crossmatch test." This determines whether the recipient's serum "kills off" the donor's cells. If the cells are destroyed, then the recipient's immune system would reject the kidney.

Crossmatch tests are also performed a week before surgery because the results may change. If the crossmatch is not favorable at a certain time, it may be so in the future.

Once the crossmatch and the tissue typing are determined, donors will need further testing. We encourage all donor work-ups to be completed at the University of Maryland Medical Center. Patients who live near and far are able to complete the work-up in less trips if carried out at the Medical Center. For those donors living greater than 75 miles away, a local physician of their choice may be contacted to complete the donor work-up.

The information that is needed includes a medical history and a physical, which entails a blood pressure check to ensure a donor does not have any undesirable health conditions.

A series of laboratory and X-ray tests, as well as an EKG, will be done to screen for kidney function, liver function, hepatitis, heart disease, lung disease and other viruses or infections. Urine testing will also be done to make sure the kidneys function normally. Other tests may be necessary depending on the results of these studies.

If the doctor agrees a potential donor is a good candidate, a CT angiogram (a computerized tomography) scan will be completed. During this scan, dye is injected into the blood stream through a vein in the arm. The dye travels to the kidneys and urinary tract while the CTA scan and X-rays are done. These tests help the transplant staff determine if the urinary tract, kidneys and the blood vessels leading to the kidneys are normal. These procedures are done in the hospital on an outpatient basis. It takes about an hour, and potential donors may drive themselves home afterwards.

We encourage all donors to have testing completed at the University of Maryland Medical Center. Tests by other radiologists must be done under the direction of protocols facilitated by the Medical Center's transplant coordinator. Keep in mind the CTA may need to be repeated by the Medical Center's Radiology Department if radiographic views are not adequate.

WHAT ARE THE HEALTH RISKS ASSOCIATED WITH BEING A DONOR?

Death resulting from kidney donation is rare. Donating a kidney does not change life expectancy, nor does it increase the risk of developing kidney disease. Research to date on living kidney donations finds that kidney donation does not appear to put donors at any future risk for health problems.

WILL GIVING A KIDNEY AFFECT A DONOR'S LIFESTYLE?

A person can lead an active, normal life with only one kidney. Studies have shown that one kidney is good enough to keep the body healthy. After recovering from surgery, a donor can work, drive, exercise and participate in sports. A donor can continue in all types of occupations, including military duty. Also, being a donor does not impact a person's ability to have a child.

DO DONORS HAVE TROUBLE KEEPING OR GETTING INSURANCE FOLLOWING DONATION?

Donors should not have difficulty maintaining or obtaining life, health or disability insurance following kidney donation. A survey of insurance companies indicated that the cost of insurance does not increase, and another survey of donors found that roughly 98 percent encountered no problems with insurance. Donors are encouraged to check with their insurance companies to verify their policy.

FOLLOWING THE SURGERY

WHAT HAPPENS AFTER SURGERY?

A donor will wake up in the recovery room feeling groggy and perhaps uncomfortable. He or she will be wearing an oxygen mask and have a catheter draining urine from the bladder to a collecting bag. It is important to accurately measure the kidney's urine output. The catheter is usually left in overnight.

Medicine for pain will be given orally.

A donor is encouraged to get out of bed as soon as possible – usually the night of surgery. Walking is expected the next day.

A donor will be released from the hospital one to two days following the operation. He or she will have a check-up one to two weeks later.

WHAT SHOULD A DONOR EXPECT DURING RECOVERY AT HOME?

Donors are encouraged to be as active as possible, taking rest periods during the first few days. They should not lift anything heavier than 20 pounds for the first six weeks.

A donor can typically return to work two to three weeks after surgery, depending on the type of work.

Walking is very good exercise and encouraged. A donor should not do anything that makes him or her feel uncomfortable. It is important to take the time to recuperate fully.

WHAT EMOTIONS DO DONORS FEEL AFTER SURGERY?

Many donors say they feel very positive about the experience because they have helped the recipient. However, it is not uncommon for donors to experience some depression after donation. These feelings are more likely to occur in cases where the outcome of the surgery does not meet the expectations of the donor and/or recipient. It is important to learn as much about donation as possible so that a donor can make an informed decision.

WHO PAYS FOR THE MEDICAL COSTS?

As a donor, medical costs are covered by the Transplant Department at the University of Maryland. The Department will cover 100 percent of the donor's medical bills, including pre-transplant evaluation, hospitalization and follow-up medical care for at least three months after the operation. It is important that the donor present the billing form prepared by the transplant financial coordinator prior to all testing. Donors should not at any time furnish private insurance information.

ARE THERE ANY EXPENSES NOT COVERED?

Lost wages, childcare or daily living expenses that are incurred during testing before the surgery and during follow-up visits after the operation are not covered. In most cases, the donor transplant coordinator can arrange lodging for far away donors. It is important to discuss all potential financial consequences of donation with the donor social worker.

**For more information, call 410-328-3444
or 1-800-492-5538 5538 (ask to speak with
a pre-evaluation transplant coordinator.)**



**THE DIVISION OF
TRANSPLANTATION
AT THE
UNIVERSITY OF MARYLAND
MEDICAL CENTER**

If you would like to speak with a past living donor,
please contact the transplant coordinator at
410-328-5408 or 1-800-492-5538

22 South Greene Street
Baltimore, Maryland 21201
www.umm.edu/transplant

Appendix B:
2006 Promoting the Partnership Symposium Report

**The Maryland Commission on Kidney Disease and Transplantation
Promoting the Partnership Symposium, October 3, 2006**

**Summary from Workgroup Session A1:
“Obtaining and Sending Transplant Clot Samples”**

The following items were discussed during this breakout session:

- Payment for sending the specimens back to the transplant center
 - Resolution; UMD already pays for their patients. JHH will begin within 2 months
- What is included in the kits?
 - The mailer, labels for the patient, the red top tube or tiger top tube.
- Should Dialysis Units spin the sample
 - It is helpful if they do to reduce hemolysis, but it is not necessary. It is more important to send the specimens the same day they are drawn rather than hold them at the units. If you must store them for any length of time, do so in a refrigerator. Do not freeze.
- Provide a Dialysis Center Liaison person to each of the laboratories
- Improve communication
 - Dialysis units say they have difficulty reaching a real person.
 - Newsletter article detailing the monthly specimen procedures
 - Dialogue to routinely exchange clinical information and patient status between TPL centers and Dialysis Units
 - Routine exchange of lists with the dialysis units so everyone is on the same page
- Assignment of responsibility with regards to transplant patient management. (This was sort of off track with our session but stemmed from the inability of the dialysis units to contact the transplant centers.)
- Formalize the requirements so they are the same across both centers.
 - This will take a little bit of effort on the parts of the transplant centers to communicate effectively exactly what is required.

This session was facilitated by:

Lisa Owens, RN, BSN of University of Maryland
John Hart, MBA, CHS of Johns Hopkins

Questions about workgroup session A1 summary?

Please contact: John Hart, Email: hartjm@jhmi.edu, ph: 410.955.3600

**The Maryland Commission on Kidney Disease and Transplantation
Promoting the Partnership Symposium, October 3, 2006**

**Summary from Collaborative Workgroup Session B1:
“Coordination of information about compliance, psychosocial and financial/coverage”**

The following items were discussed during this breakout session:

- Idea that patients should be encouraged to take control of their care.
- Some concern about patients who need added measure of support
 - Recommendation that dialysis and transplant staff assess patient’s individual abilities at any given time during the transplant process
- Concern about raising issues of “compliance” about patients.
 - Noted that mentioning compliance issues can be through informal conversation, acknowledgement that raising compliance issues was important so that transplant social workers could have more in depth consultation with potential patients, and may allow them to develop an “action plan” to address issues throughout transplant.
- Acknowledgement that the transplant liaison at the dialysis unit should always have regular communication from the transplant center about patient status
- Transplant center to consistently communicate to dialysis center what information needed on patient so that transplant is not delayed
- Dialysis-transplant community needs a tool to help track the status of the patient.
 - Discussion about a “Patient Status List” tool, a list that is distributed to dialysis units from transplant centers every other month
 - Decided that this tool should be provided to all dialysis units and that it should include demographic and insurance information in addition to the status of the patient.

Next steps:

- UMMS collaborative workgroup facilitators to confer with UMMS transplant leadership about creating a patient status tool
- JHH to revise format of its current patient status list to include revisions from collaborative discussion & send lists to all dialysis units in the state of Maryland every other month.
- Transplant liaisons in dialysis community to review patient status lists/ provide feedback on information that is inaccurate or incomplete on the list.

This session was facilitated by:

Zendy Williams, LGSW & Chelsea Quinn, LGSW of University of Maryland
Rose Mary Gall, RN, BSN of Johns Hopkins

**The Maryland Commission on Kidney Disease and Transplantation
Promoting the Partnership Symposium, October 3, 2006**

Summary from Workgroup Session A2:

“Coordination of information about patient status: waiting on the list, hospitalizations or changes in health status, death, transplantation, etc.”

The following items were discussed during this breakout session:

- Wait time for each blood group
- What dialysis centers would like from the transplant centers in terms of information, contacts, etc.
- How dialysis centers can take a more proactive role in referring patients for transplant evaluation
- How & when the dialysis units & patients should be contacting the transplant center
- What happens if a patient declines an organ offer
- Questions arose re: the Network expectation of transplant education in the dialysis facility and what qualified, i.e. handing the patient a pamphlet vs. more detailed info.
- There was discussion about making sure each facility was aware that a policy for managing transplant referrals was in place
- Discussion re: who in the facility was more comfortable, experienced, interested, appropriate to be the transplant liaison in the facility, generally RN vs. MSW?
- Sample medical record transplant documentation tools were shared

Next steps:

- It was discussed how email is the most expeditious way to contact the transplant centers. This was more of a learning how we each work & how to work together better.
- Dialysis units requested that when transplant centers send them a copy of the patient’s transplant evaluation “workup” still to be completed letter, that the transplant center also includes the transplant physician’s notes from his/her evaluation of the patient
- Transplant Centers to conduct more patient in-services about transplant
- Establish who the dialysis facilities can contact in order to get a copy of the hospital transplant policy which the Network requires each facility to have on site.

This session was facilitated by:

Janet Anderson, MSW, LGSW of Davita
Lisa Owens RN, BSN of Univ. of Maryland
Kate Knott, RN, BSN of Johns Hopkins

**The Maryland Commission on Kidney Disease and Transplantation
Promoting the Partnership Symposium, October 3, 2006**

**Summary from Workgroup Session B2:
“Developing education materials to address patient questions about transplantation”**

The following items were discussed during this breakout session:

- Education about the process of evaluation and workup needs to be reinforced
- Consistent “introduction to transplant and getting through the workup” program would help the dialysis nurses and patients all.
- Dialysis staff request information to help the patient with understanding how to decide whether or not transplant is the therapy for them.
- Identification of patients’ frequently asked questions & concerns
 - How soon until the transplant?
 - Who is the transplant contact person?
 - How much transplant cost?
 - Does the patient have adequate coverage?
 - Will the insurance cover the transplant?
 - How long will I be in the Hospital?
 - How long will the kidney last?
 - How will Transplant improve the patient’s quality of life?
 - Patients hear horror stories of other patients (only transplant role models are the failures.)
- Identification of teaching methods such as posters, flyers, to help teach patients about transplant.
 - Video
 - Mentoring (have successful transplant patients visit dialysis units)
 - Written materials
 - Interactive and visual materials
 - Should be realistic
 - Should be balanced – pro’s and con’s

Next steps:

Develop an email group to continue to share and collaboratively develop patient education.

This session was facilitated by:

Linda Wood, RN, BSN of University of Maryland

Susan Humphreys, RN, MS of Johns Hopkins