Financial Information for Kidney and/or Pancreas Transplantation

Transplantation is an expensive treatment for kidney and/or pancreas disease and it is important for you to plan ahead and be well informed of your needs and your coverage. You will need to have a comprehensive plan to be prepared for the costs of the transplant workup, the transplant inpatient stay, post-transplant follow-up care, and the high cost of anti-rejection medications which you will need for the life of your transplant.

Throughout the transplant process a **transplant financial coordinator** will work with you on coverage, insurance issues and financial issues. You will begin working with them as you make your evaluation appointment. They may assist you in many areas, including:

- Determining your current coverage
- Identifying the additional coverage you may need
- Making sure an authorization is in place for your transplant
- Providing the documentation necessary to allow you to apply for ESRD Medicare after your transplant, if you didn't have Medicare before transplantation

You will also work with a **transplant social worker** who will provide support to you and your family in a variety of ways as you navigate the transplant process. Transplant social workers can help you in many areas, such as:

- Assess financial barriers to transplant, such as transportation and out-of-pocket costs, and work with patients and family to identify available resources
- Provide information regarding federal, state and local programs, as well as transplant-specific resources such as the National Kidney Foundation, the American Kidney Fund and Help Hope Live
- Direct patients after transplant to local job retraining services such as Michigan Rehabilitation Services

Transplant financial coordinators and transplant social workers work together to help you manage the financial and insurance aspects of transplant.

Planning For Your Transplant Financial Obligations

The first step in financial planning is finding out what your insurance covers. You will need to call your insurance company and ask what your benefits are for transplant services. There are many phases of transplant, such as the transplant admission, outpatient appointments, medical procedures and prescriptions, and each may have a different level of coverage. There may be maximum allowable limits or exclusions for certain services. To help you communicate with your insurance company, we have provided a questionnaire to guide you in your coverage discussions for each phase of transplant. This questionnaire can be found at the end of this section.

When planning ahead, there are some important things to consider that may change over time with your coverage. Be sure to consider changes that may result from:

- Divorce or separation from a spouse can lead to cancellation of coverage on the spouse's policy
- Changes that may impact the insurance coverage; change in job status due to health, layoff or other causes
- Changes in the patient's insurance policy that can lead to increased co-pays and/or deductibles
- Children reaching the age of 26 and no longer being covered under their parents' insurance or state-funded health plans

Out-of-Pocket Expenses to Consider

Being prepared by having a financial plan is the key to minimizing the financial strain and stress to you and your family as you go through the transplant process.

Once you have determined what your insurance covers, you'll have a better understanding of the out-of-pocket medical expenses you should anticipate. In addition you may need to pay for other expenses, often considered "non-medical," which may include:

- **Transportation** to and from the transplant center for frequent follow-up visits
- Temporary **lodging** and **meals** for family members during and after the transplant
- **Parking** fees for visits to the transplant center
- Insurance **premiums**, **co-pays** and **deductible** amounts
- Possible **loss of income** while out of work for the transplant
- **Child care costs**

Some insurance companies provide reimbursement for transportation, meals and lodging expenses directly related to transplant services. It is important to contact your insurance company to see if these benefits can be provided under your policy.

Referrals and Authorizations

Health Maintenance Organizations (HMOs)

Health Maintenance Organizations (HMOs) require patients to have a referral from their primary care physician (PCP) before seeing a specialist. A referral is documentation from the Primary Care Provider that they are "referring" the patient to a specialist. The patient must get the referral before the date of the appointment. Without a referral the HMO will not pay for the visit and the patient will be responsible for the bill.

In addition to PCP referrals, some insurance companies require **prior authorization** to begin the transplant process. The patient should call his/her insurance company before making the initial appointment to see what is required by the insurance company.

Networks

Many insurance companies are part of a larger network of hospitals and doctors. Insurance companies often contract with transplant networks to manage their transplant cases. Some insurance networks will not approve transplants at the University of Michigan, and will require patients to use a transplant center within their network, even if the preferred center is in another state.

Insurance Changes

If your insurance changes while you are on the transplant list, it is important to call the transplant financial coordinator to report the change. Organ transplants require written approval from the insurance carrier before the transplant. If a change in insurance has occurred and no authorization is in place, the patient is responsible for full payment of all services rendered. The authorization process is lengthy; the sooner an insurance change is identified the faster the patient can be re-authorized through the new insurance carrier.

In addition, it is recommended that you contact the transplant financial coordinator before making any changes during an open enrollment period. If you fail to let us know about changes in your insurance, you risk being put on HOLD on the wait list until your new insurance can be verified and a new authorization for your transplant is obtained.

ESRD Medicare

Medicare is a federal government health insurance program designed to help patients age 65 and over, those who have been totally disabled for two years, or people who have End Stage Renal Disease. Even if you have group health insurance, Medicare can help cover the costs that insurance does not pay. This includes office visit co-pays, annual deductibles and out-of-pocket expenses that you may owe in a calendar year. Your transplant financial coordinator can help you to understand how Medicare can help cover balances not paid by your insurance.

Entitlement to Medicare

Entitlement to Medicare is based on three factors:

- **Age**: 65 years old
- **Disability**: Inability to work for 24 months (age is not a factor)
- **End Stage Renal Disease (ESRD)**: Being on dialysis and/or kidney transplant* (age or disability are not factors)

* If you have Medicare solely as a result of ESRD, your Medicare will end three years after a successful transplant.

Eligibility for Medicare

To be eligible for Medicare, you (or your spouse or parent for young adults under age 22) must have worked long enough and paid into the Social Security system. The length of time (work units) required to qualify for coverage is different between age, disability and ESRD entitlement. Fewer work units are required for ESRD entitlement. Other important factors are citizenship or legal residency.

A person can qualify due to age or End Stage Renal Disease if they are the spouse of a worker who has earned enough credits provided they have been married for at least one year and are still married, or if divorced, must have been married for at least 10 years.

A minor (unmarried) child under the age of 22 who has end stage renal disease can be covered under a working parent, as long as enough work credits have been earned by either parent.

As a young person with End Stage Renal Disease makes the transition into adulthood, they may lose coverage under the parent's group health plan. Furthermore, Medicare coverage will end three years after a successful transplant. Therefore, careful planning will be required to make sure the patient has the continuous coverage they need for transplant follow-up care and anti-rejection medications.

If you are uncertain if you will qualify for ESRD Medicare coverage you should call **(800) 772-1213**, or go to **www.medicare.gov** for more information.

Enrolled in Medicare

Medicare enrollment is when an individual entitled to Medicare coverage has formally enrolled in Part A, Part B and/or Part D through his/her local Social Security Administration office and has received a Medicare card.

Medicare Coverage

Medicare Part A

Coverage under Medicare Part A pays for inpatient hospital facility charges such as room and board, testing, operating room costs and supplies while you are in the hospital. Medicare Part A will pay 100 percent of covered expenses after the inpatient deductible is met for the first 60 days of confinement. Then daily "coinsurance" rates apply. There is no monthly premium for Part A. If you have primary coverage through an employer group health plan, Medicare Part A will pay 100 percent of covered costs not paid by your primary carrier during your inpatient hospitalization.

Medicare Part B

Medicare Part B will cover 80 percent of all inpatient and outpatient doctor bills, and 80 percent of outpatient medical expenses (if Medicare is primary). Medicare Part B will also pay 80 percent of your anti-rejection medications as long as you have Medicare to cover the month you received your transplant. If you have primary employer group coverage and Medicare is your secondary coverage, Medicare Part B can help pay for your prescription co-pay amounts for anti-rejection medications after your transplant, as well as office visit co-pays, annual deductibles and cost shares that you may otherwise need to pay.

There is a monthly premium for Medicare Part B coverage. The Social Security Administration will bill you quarterly (every three months) for Part B coverage.

To avoid enrollment delays, it is important that you work with your financial coordinator to figure out the best time for you to sign up for both Medicare A & B.

Medicare Part D – Prescription Drug Coverage

Medicare Part D is the prescription drug plan implemented by the federal government on January 1, 2006. If you are on Medicare and do not have prescription coverage, you need to enroll in Part D. If you do not enroll in Part D when eligible and do not have better prescription coverage than they offer, they will penalize you 1 percent of the premium payment for each month you do not enroll. So for example, if you are eligible and wait a year, you will pay a premium that is 12 percent higher than if you enroll at the time of eligibility.

There are restrictions on when you can enroll in Medicare Part D. When you are first approved for Medicare coverage, you can enroll in a plan three months before the effective date, and up to three months after that original effective date. Beyond that, you are limited to an open enrollment period.

There are many Medicare Part D plans to choose from. These plans have monthly premiums that range from $25 to $60 per month and you will have co-pay amounts that you need to pay. Once you have incurred a certain amount of prescription costs, there is also a period of time referred to as the "donut hole," where you will need to pay for 25 percent of your prescriptions covered by Medicare Part D. Once you reach an out-of-pocket maximum, you will then have "catastrophic coverage" where medications will be covered at 95 percent. The premium, co-pay and out-of-pocket amounts change each year. You will need to be prepared to cover the out-of-pocket costs under Medicare Part D.

When applying for Medicare Part D, we recommend that you apply for the "Extra Help" benefit. You can learn more about getting extra help with Part D costs by calling **(800) 633-4227**, contacting your local Social Security Office or visiting **www.medicare.gov**. Extra help benefits are based on your income limits and can greatly reduce your out-of-pocket costs.

If you are on Medicare Part A and Part B at the time of your transplant, Medicare Part B will pay for the immunosuppressive medications (80 percent), and Part D will only be paying for your non-immunosuppressive medications. If you are NOT on Medicare at the time of transplant, but obtain it later with Part D, then Part D would pay for both immunosuppressive and non-immunosuppressive medications. This is a very important point to understand about Medicare coverage for medications.

Prescriptions and Medicare Part B/Part D

ON MEDICARE At the time of transplant	**NOT ON MEDICARE** At the time of transplant – Have Medicare coverage now
Anti-rejection drugs paid by: Medicare Part B and supplemental coverage	Anti-rejection drugs paid by: Medicare Part D or regular prescription coverage
Other medications paid by: Medicare Part D or regular prescription coverage	Other medications paid by: Medicare Part D or regular prescription coverage

ESRD Medicare - 36-Month Limit

If you have Medicare solely as a result of End Stage Renal Disease, **your Medicare will end three years after a successful transplant**. Since having continuous medical coverage is so important to the success of your transplant, you will need to plan carefully during your three-year coverage period to ensure you will continue to have coverage after the three-year period ends. If you have Medicare as a result of being disabled from another health condition, your Medicare coverage may extend beyond the three-year limit.

If you are on Social Security Disability solely due to End Stage Renal Disease, your disability status will more than likely be reviewed within a year after a successful transplant. This may affect your eligibility to continue receiving monthly disability checks.

As soon as you are physically able to return to work, contact your transplant social worker who can help you in making plans for retraining. If your primary care physician states that you have other medical conditions that cause you to be unable to work, contact Social Security to apply for disability related to those medical conditions.

Other Medicare Facts

If you continue to have Medicare three years after your transplant due to age or Social Security Disability, then Medicare Part B can continue to help pay for anti-rejection medications as long as you continue to have Medicare Part B coverage, and if you had Medicare at the time of the transplant.

Your transplant financial coordinator is knowledgeable about Medicare coverage, and is available to help you when making decisions about applying for Medicare.

Secondary Insurance is Necessary

Medicare coverage alone is not sufficient to cover the cost of transplantation. If you have Medicare, you will need to apply for a supplemental policy to help cover the costs your Medicare will not pay. Your transplant financial coordinator or transplant pharmacy financial coordinator can help you with resources to find a supplemental policy that will help cover your transplant needs.

The 30-Month Coordination Rule

If you have group health insurance through an employer, you will need to be aware that Medicare will be the secondary payer for the first 30 months. After the 30-month period, Medicare will become primary over the group health plan. You MUST have Medicare Part A and Part B in place when the 30-month coordination period is over, since your group plan is no longer obligated to pay as your primary carrier. Remember, having Medicare even as the secondary payer during the 30-month coordination period, will help pay for co-pays and deductibles not paid by your group health insurance.

Health Exchanges

The University of Michigan Health System has certified counselors who are trained to help you navigate through the changes taking place due to the implementation of the Affordable Care Act (ACA). If you have questions about how these changes may affect your situation, please call **(877) 326-9155**.

Medicaid

Medicaid is an option that has been expanded recently due to the changes contained in the Affordable Care Act (ACA). You may qualify for Medicaid coverage based on household income and size. If your income is at or below 133 percent of the federal poverty level for the number of people in your family, you may be eligible. Being disabled, the amount of household financial assets and whether or not you care for minor children are no longer part of the eligibility equation, beginning in 2014.

Applying for Medicaid can be done through the Department of Human Services Office in the county where you live.

Children's Special Health Care Services (CSHCS)

The CSHCS program is part of the Michigan Department of Public Health. It provides healthcare benefits to patients under the age of 21 who are residents of Michigan and have a qualifying chronic disease. The benefits may include lodging and transportation, as well as payment of medical expenses, including transplant services. An affordability scale is used to decide whether families will receive free services, or be expected to share in the cost of their child's care. Please contact your transplant social worker for more information about this program, and for assistance in the application process.

Prescription Drug Coverage

Prescription coverage is often the number one financial problem patients face after transplant. Immunosuppressant medications are expensive, costing between $2,000 and $4,000 per month, and must be taken for the life of the transplant. Transplant patients generally take many medications immediately following transplant. Often the medications may decrease in dose and in the number of medications taken over a period of time following the transplant. After your transplant, you will typically take a combination of at least three immunosuppressive medications that could include the following:

- Cyclosporine (Neoral®, Gengraf®)
- Sirolimus (Rapamune®)
- Tacrolimus (Prograf®)
- Envarsus
- Mycophenolate (Cellcept®)
- Mycophenolic acid (Myfortic®)
- Azathioprine (Imuran®)
- Prednisone
- Everolimus and Rapamycin

Many patients will also need to take an antiviral medication called Valcyte® for three to six months following transplant. This medication is not an immunosuppressive drug and will cost approximately $2,000 per month.

It is important to note that for many insurance plans Valcyte® is considered a specialty medication and may be subject to a higher co-pay amount. Individuals covered by Part D and who need Valcyte® can expect to fall into the donut hole fairly quickly and need to plan for how to continue to pay for this medication for the following months. The financial coordinator or social worker can talk to you about making a plan for Valcyte® if this out of pocket expense is not affordable.

Please remember that the University of Michigan Transplant Center is not responsible for coverage of your medications after your transplant.

If you find yourself without insurance after transplant, contact the Transplant Specialty Pharmacy as soon as possible. They can review with you some possible resources to help with the cost of transplant medications.

Donation Costs for Living Kidney Donors

Members of your family or friends who generously offer to be evaluated as kidney donors are not responsible for any medical bills incurred for their donation work-up, surgery, prescriptions, or follow-up care related to donation. The regulations for handling living donor services are complex. We will bill living donor services per the regulations, but do not bill them to the donor or their family. Because it is sometimes difficult to identify all the charges incurred by potential kidney donors, it is important to contact your transplant financial coordinator at once if your donor mistakenly receives a bill.

Fundraising Opportunities

If for any reason, you struggle with the costs associated with your transplant, you may want to consider fundraising. Fundraising is best done before the transplant when you are feeling better, instead of while you are trying to recover from major surgery. There are two ways to protect money raised by friends and family to be used solely for your medical expenses; using a non-profit fundraising organization or setting up a legal trust. There are groups that specialize in helping transplant recipients in raising funds to cover their out-of-pocket expenses. A huge benefit to using a fundraising group is to protect the money you raise from being taxed. If you directly accept funds that have been raised, they are considered taxable income. While the fundraising groups do keep a small percentage of the funds donated for their operating costs, the amount they keep is significantly less than you would pay in taxes. Funds raised by these groups allow more of the funds to be available for your transplant costs. Also, if you are on Medicaid, monies accepted directly by you will be considered income and will affect your financial eligibility and may disqualify you for Medicaid.

There are two main groups that our patients use to assist them in their fundraising efforts.

- Help Hope Live, **(800) 642-8399, www.helphopelive.org**
- National Foundation for Transplants (NFT), **(800) 489-3863, www.transplants.org**

Stay in Contact with Your Financial Coordinator

It is very important that you stay in contact with your transplant financial coordinator, not only to report a change in insurance, but for any insurance or financial issue that may have an impact on the success of your transplant. The transplant team is invested in helping you maintain a healthy transplant.

Transplant Prescription Coverage Information

After your transplant, prescription coverage will become even more important to you than it is now. To prevent your body from rejecting your new organ, you will need to take immunosuppressive (anti-rejection) medications, along with a variety of other medications, for the rest of your life. Many of these medications are very expensive. Without drug coverage the average cost for these medications is between $2,000 to $4,000 per month. It is vital that you have adequate prescription coverage or are in a position to cover these expenses out of pocket.

To support our patients after their transplant, the University of Michigan Transplant Center and the Department of Pharmacy created a Transplant Specialty Pharmacy (TSP). The TSP was developed to help you navigate the complexities of your medications and insurance coverage. Benefits of enrolling in the TSP include: ongoing and timely access to your

medications, proper billing of your medication and financial counseling focused on minimizing your out-of-pocket expense. After transplant, you will meet with a TSP financial counselor who will explain the program in greater detail. At that time, we will provide you with detailed information regarding your pharmacy benefits, whether or not your plan will allow you to participate and if interested, enroll you in the program.

At this time, if you currently have prescription coverage you should already be aware of what your prescription co-pay expenses are, and if you are required to fill prescriptions at a specific, plan-approved pharmacy. In addition to retail pharmacy benefits, you may also have a "mail order" option for your prescription needs. Mail order plans allow you to fill a two or three-month supply at one time, and may offer a cost saving incentive. If you are not familiar with your coverage, it is imperative that you find out.

Medicare Part B will cover 80 percent of the anti-rejection medications if needed. To take advantage of this coverage, Medicare must either be in place or you are eligible for retroactive coverage at the time of transplant. Medicare supplement policies are available that would cover the 20 percent balance on those anti-rejection drugs after your transplant. Between Part B Medicare and a supplement plan, anti-rejection medications should be covered in full.

Medicare Part D is a prescription coverage option that may be available to you as well. There are a variety of plans to choose from offering some assistance for your non-immunosuppressive medication needs. Learn more about this coverage either by calling **(800) 772-1213** or visit **www.medicare.gov**.

Medicare Part D plans do not provide full coverage. Unless you qualify for the "extra help" program the following information applies: You will have a $310 annual deductible. Then Part D will pay a percentage (varies based on plan choice) toward your prescription needs for the first $2,830 in total drug cost. You will owe approximately $630 during this time. The next $3,610 in drug needs will be your responsibility to pay in full. Once the total annual drug cost has reached $6,440, Medicare Part D will pay 95 percent of your prescription needs. Learn more about the "extra help" program by visiting **www.ssa.gov/prescriptionhelp**.

If you do not have prescription coverage when you get your transplant, you will need to be prepared to pay for your medications. If you lose your prescription coverage after transplant, you may be eligible for medication assistance programs. Programs are offered by some of the drug manufacturers, are intended to help on a temporary basis and cannot be relied on for continuous coverage. There are also "transplant assistance organizations" that promote fundraising, which may be very helpful for you.

Your financial coordinator, social worker and TSP representative are part of the transplant team here at MM. They are available to help you work through insurance or prescription coverage issues.

Worksheet: Preparing Financially for Prescription Coverage: Kidney/Pancreas Transplant

General Co-pays:

Generic: $_____

Brand Name: $_____

Non-preferred brand: $_____

Co-pays for Specific Medications:

Drug Name/Strength	Quantity		Comments
*Tacrolimus 5mg	60 tablets for 1 month	$_____	_____
*Tacrolimus 1mg	240 tablets for 1 month	$_____	_____
*Tacrolimus .5mg	60 tablets for 1 month	$_____	_____
*Mycophenolate 500mg	120 tablets for 1 month	$_____	_____
	(If African American) 180 tablets for 1 month	$_____	_____
*Prednisone 5mg	60 tablets for 1 month	$_____	_____
Valcyte 450mg	60 tablets for 1 month	$_____	_____
Omeprazole 20mg	30 tablets for 1 month	$_____	_____
Nystatin 473ml	100,000 units (usually only comes in one size oral solution) for 1 month	$_____	_____
Bactrim 400-80mg	30 tablets for 1 month	$_____	_____

**Patients with Medicare Primary will not need to ask for these prices, as they are covered by Part B.*

Important Phone Numbers and Websites:

- **Blue Cross Medigap**
  (855) 237-3501
  www.bcbsm.com/index/health-insurance-help/contacts.html

- **Medicare**
  (800) 633-4227
  www.medicare.gov

- **Michigan Department of Human Services (DHS-Medicaid)**
  (800) 642-3195
  www.michigan.gov/mdhhs

- **Michigan Medicine Information**
  (734) 936-4000
  www.uofmhealth.org

- **University of Michigan Transplant Center**
  (800) 333-9013
  www.uofmhealth.org/transplant

- **Extra Help (Social Security Admin.)**
  (800) 722-1213
  www.ssa.gov/benefits/medicare/prescriptionhelp/

Understanding Your Insurance Coverage — Questions to Ask Your Insurance Representative

Name of Representative _____ Date _____

BENEFITS/COVERED SERVICES	YES/NO	NOTES
Does my plan cover hospital charges?	Yes No	
Does my plan cover professional charges (also known as doctor fees)?	Yes No	
Does my plan cover prescription drugs?	Yes No	
Does my plan cover solid organ transplantation?	Yes No	
Does my plan have a "pre-existing condition" clause? If yes: How is the clause defined? If yes: Would my illness be considered a pre-existing condition?	Yes No Yes No	

BENEFITS/COVERED SERVICES	YES/NO	NOTES
For liver and kidney transplant only:		
Does my plan cover *living related* solid organ transplant?	Yes No	
If yes, does my plan cover the donor medical charges?	Yes No	
If yes, are there limits on the coverage for donor medical charges?	Yes No	
If yes, what are the limits?		
Does my plan limit the number of transplants payable in a lifetime?	Yes No	
If yes, what is the limit?		
If yes, does that limit apply for each organ?	Yes No	
Does my plan have a maximum *annual* amount it will pay out each year?	Yes No	
If yes, what is the maximum amount?		
Does my plan have a maximum *lifetime* amount it will pay out over a lifetime?	Yes No	
If yes, what is the maximum amount?		
Are there coverage exclusions in my plan?	Yes No	
If so, what are the exclusions?		
What period of time applies to the exclusion?		

BENEFITS/COVERED SERVICES	YES/NO	NOTES
Does my plan cover any travel, meals and lodging expenses? If yes, does it cover for a family member as well as the patient? If yes, how much does it cover?	Yes No Yes No	
OUT-OF-POCKET COSTS	**YES/NO**	**NOTES**
Does my plan have deductible amounts? If yes, what are they?	Yes No	
Does my plan have copayment amounts? If yes, what are the amounts? If yes, what services do they apply to?	Yes No	
Is there a maximum out-of-pocket amount that I would be responsible for each year? If yes, what it the limit?	Yes No	
REFERRALS/AUTHORIZATONS	**YES/NO**	**NOTES**
Does my plan have any restrictions on which medical centers I can use (designated provider network)? If yes, is Michigan Medicine an approved provider?	Yes No Yes No	

REFERRALS/AUTHORIZATONS	YES/NO	NOTES
Will my plan cover my services at an out-of-network provider? If yes, will my out-of-pocket expenses be higher?	Yes No Yes No	
Does my plan utilize a network for managing transplant services? If yes, is the University of Michigan Transplant Center an approved provider?	Yes No Yes No	
Does my plan cover a consultation at one or more transplant centers?	Yes No	
Is a referral or authorization required for: Consultations? Transplant Evaluation/testing? Medical Procedures?	 Yes No Yes No Yes No	
Who will be my case manager? How can I contact the case manager?		

PHARMACY	YES/NO	NOTES
Does my plan cover outpatient prescriptions? If so, how much are the copays?	Yes No	
Are prescriptions available by mail order? If so, how much are the copays?	Yes No	
Is there an approved list of covered medications? Will the plan ever approve use of medications as exceptions to the list? If yes, how is an exception requested?	Yes No Yes No	