Financial Aspects of Kidney and/or Pancreas Transplantation

Transplantation is an expensive treatment for renal 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 prior to 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 assist you in many areas, such as:

- Assess financial barriers to transplant, such as transportation and out-of-pocket costs, and work with patient 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 the National Transplant Assistance Fund
- Direct patients after transplant to local job retraining services such as Michigan Rehabilitation Services
- Help patients at risk of losing their transplant due to loss of prescription coverage to access emergency assistance as well as pharmacy assistance programs

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 in the "Resources" section of this Patient Education Guide.

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:

- Reaching the maximum limit the insurance company will pay per year or per lifetime
- 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, change in student status or other causes
- Changes in the patient's insurance policy that can lead to increased co-pays and/or deductibles
- Children becoming adults 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) prior to seeing a specialist. A referral is documentation from the Primary Care Provider that they are "referring" the patient to a specialist. The patient must obtain the referral prior to 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 their insurance company prior to making the initial appointment to see what is required by their insurance company.

Networks

Many insurance companies are part of a larger network of hospitals and physicians. 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 the patient 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 prior to 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 prior to making any changes during an open enrollment period. You must also remember that if you have a lapse in coverage between policies, the new policy may include a waiting period which

could leave you without coverage for a period of time. Be certain your existing coverage stays effective, even if you must pay premiums through COBRA, until the start date of the new coverage. Finally, 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 assist 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.

Medicare will only cover a pancreas transplant if it is in combination with a kidney transplant. Medicare will also cover if you have had a kidney transplant, and then later receive a pancreas transplant. Medicare will not pay for a "pancreas alone" transplant.

Included in this packet is a booklet called "Medicare Coverage for Kidney Dialysis and Kidney Transplant Services." This booklet will provide answers about Medicare and how it will help pay for dialysis and transplant services.

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**: Being on dialysis and/or kidney transplant (age or disability are not factors)

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** on the web 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 their 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 physician 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 at the time of the 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 penalties (increased premium rates) at a later date, it is important to enroll in Medicare Part B at the same time you enroll in Medicare Part A for End Stage Renal Disease.

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 prior to 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 100 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) MEDICARE**, contacting your local Social Security Office or online at **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.

As soon as you are physically able to return to work, contact your Transplant Social Worker who can assist 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 costs 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 Social Worker can assist you with resources to help you 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.

Medicaid

If you find that your current insurance coverage does not cover you sufficiently, or if you are losing your group health insurance coverage, Medicaid may be an option for you. Patients must qualify on two levels to be considered for Medicaid.

- Financial Status Qualifications: Your income, the number of people in your home and your assets will be considered in qualifying based on financial status. You may qualify if you have a low income and no large assets (one home and one vehicle are exempt). All patients must qualify on the basis of their financial status to be considered for Medicaid coverage.
- Other Qualifications – Patients must qualify for one of the following in addition to qualifying based on financial status:
  - **Age:** You must be under 21 years of age or over 65 years of age
  - **Health Status:** You qualify if you have been approved for Social Security Disability Income or if you are medically disabled for over one year.
  - **Minor Children in the Home**

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 health care 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®)
- Mycophenolate (Cellcept®)
- Mycophenolic acid (Myfortic®)
- Azathioprine (Imuran®)
- Prednisone

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 $1,500 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.

It is important that you keep your Transplant Financial Coordinator or Transplant Social Worker informed of any concerns that you have regarding medication coverage. If you do not have coverage and cannot afford to pay for your medications, your new organ transplant will fail.

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. Fund raising 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 assisting transplant recipients in raising funds to cover their out-of-pocket expenses. A huge benefit to using a fund raising 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 fund raising groups do retain a small percentage of the funds donated for their operating costs, the amount they retain 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 fund raising efforts.

- The National Transplant Assistance Fund, **(800) 642-8399**
- The National Foundation for Transplants, **(800) 489-3863**

For more information on financial planning and fund raising you can view a video which explains fund raising at **www.transplantfund.org**. Click on "View NTAF 'Why Fund Raise' video" for a summary of how fund raising works.

Remember – 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.