

Transplant Manual

L I M B A L A L L O G R A F T T R A N S P L A N T

TORONTO

Limbal Allograft Transplant PROGRAM



 **UHN** | Canada's
#1 Hospital

This manual is dedicated to our donors, our patients and their families

Acknowledgements

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In accordance with the Ontario *Human Tissue Gift Act*,
The Toronto General Hospital & the Multi Organ Transplant Program do not support or accept payment of any kind from patients, organizations or any party for organs for transplantation.

It is against the law to buy, sell or otherwise deal in, directly or indirectly, any tissue for transplant, or any body part or parts of the body for therapeutic purposes, medical education or scientific research.

**If at any time you are approached by a person
to purchase or sell an organ for transplantation,
please immediately contact:
Patient Relations at (416) 340-4907.**

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Welcome to the Multi Organ Transplant (MOT) Program & Your Limbal Allograft Transplant Team

The Multi Organ Transplant Program at Toronto General Hospital is Canada's largest transplant centre and performs a broad range of transplants. In 2010, the Multi Organ Transplant Program performed its first limbal allograft transplant and has performed several more since then. Led by Drs. Edward Cole and Allan Slomovic, the conjunctival limbal transplant program presents an exciting option for patients suffering from limbal stem cell deficiency.

Living donation decreases the wait times for donor eye tissue and has the advantage of ensuring that the surgery is thoroughly planned and prepared for by recipient, donor, and transplant team.

It is important that you join us in our teaching programs and share this manual with your support persons and family. Transplantation is a team effort, we are your team and you are the most important member.

Our Philosophy of Care

- We believe that our work is possible because of the generosity of organ and tissue donors. Our work must honor these remarkable gifts from donors and their families.
- We believe that respect, dignity, integrity and empathy drive care and support relationships. We expect courtesy and consideration in every interaction.
- We believe that the goal of the Multi Organ Transplant Program is to work in partnership with individuals, families, and the community to promote optimal health and quality of life for patients through all phases of transplantation.
- We believe that transplantation is a very specialized area in health care. To succeed, we need the knowledge skill and ability of our multi-disciplinary team.
- We believe that all members of the health care team make an important and valuable contribution to the plan of care. Each member of the team is a dedicated professional who continually maintains a current knowledge base and consistently strives to advance the science and art of transplantation.
- We believe that all people are unique, with their own needs, goals, and abilities.
- We believe that people achieve their optimal state of the health in collaboration with the health care team.
- We believe that information and education provide patients with knowledge to exercise their rights and responsibilities to make informed decisions about their health care.
- We believe that the best possible care is based on patient needs, available resources, and ethical principles.
- We believe that all services must be provided in a safe environment that supports health goals and enables care to be delivered with comfort and efficiency.

Our Expectations of You

Throughout your transplant experience in the Multi Organ Transplant Program at the University Health Network you have the responsibility to:

- Work in partnership with the health care team to ensure the best possible treatment, rehabilitation, discharge planning, and follow-up care
- Provide accurate information and to share any concerns with all members of the health care team
- Inform the team if you do not understand or cannot follow the health care instructions
- Respect that the needs of other patients and families may be more urgent than your own needs
- Treat staff, other patients and their families in a considerate, courteous, confidential, and cooperative manner
- Understand the University Health Network's role as a teaching and research hospital and to partner with health care professionals in training
- Smoking cessation is strongly encouraged for all of our patients

Your Transplant Team

Throughout your transplant journey, we will teach you how to care for your new tissue and your health and will support you through this process.

Your transplant team includes:

- | | |
|-------------------------------------|---------------------------|
| ➤ Doctors (Physicians and Surgeons) | ➤ Nurses |
| ➤ Social Workers | ➤ Transplant Coordinators |
| ➤ Psychiatrists | ➤ Pharmacists |
| ➤ Other health care professionals | ➤ <i>You</i> |

Some of the health care professionals that you will come in contact with are:

Ophthalmologist

An Ophthalmologist is a doctor who is highly skilled in the diagnosis and treatment of Limbal Stem Cell deficiency. This doctor, together with your family doctor, will care for you before and after your transplant. The ophthalmologist is involved in patient evaluation and selection. He/She will also perform the transplant operation, and is involved in your post-operative recovery.

Transplant Physician

The Transplant Physician works closely with your Ophthalmologist to provide care before and after your transplant. The transplant physician is also involved in patient evaluation and selection, and in particular with anti-rejection medications. This doctor, together with your Ophthalmologist and your family doctor, will manage your medications and care after transplant.

Transplant Coordinator

The Transplant Coordinator is a registered nurse or nurse practitioner who coordinates the transplant evaluation process, provides transplant education and provides follow-up care before and after the transplant. The coordinators work together with your transplant team to assess and support your progress.

Medical Secretary

The Medical Secretary is an administrative assistant who works closely along with the transplant coordinator during the transplantation assessment, prior to and after transplantation to schedule appointments. The Medical Secretary can relay concerns to the transplant team but is not qualified to give medical advice.

Social Worker

A Social Worker meets with all transplant patients and their families to review your individual situation and family supports. They will work with you and your support people to plan for your transplant.

Psychiatrist or Psychiatric Nurse

Our psychiatrists and psychiatric nurses specialize in helping patients and their families cope with chronic illness and its effects, as well as any acute psychiatric problems that might arise after transplantation. They may meet you during your transplant evaluation.

Health Care Providers outside of the Transplant Team

Your family doctor and/or eye specialist (i.e.: the family doctor or ophthalmologist who referred you to our program for transplant evaluation) are still your primary source of healthcare. It is important for you to have regular check-ups in addition to your visits with the transplant team. The transplant team will work with your family doctor or eye specialist to provide care before and after your transplant.

Transplant patients with diabetes also need to see a diabetic specialist (Endocrinologist) regularly before and after transplantation.

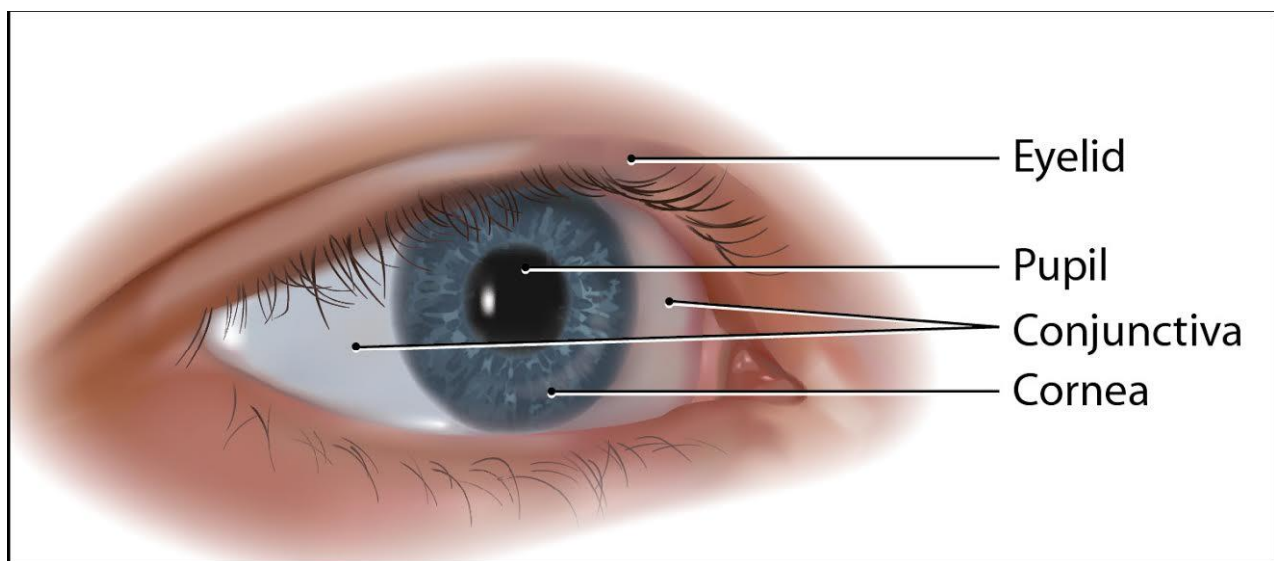
What is a Limbal Allograft Transplant?

Limbal Allograft Transplant is done to treat limbal stem cell deficiency (When the cells are damaged or don't work properly).

KLAL (Keratolimbal Allograft) is an eye reconstruction surgical procedure that involves transplanting tissue from a cadaveric donor

CLAL (Conjunctival Limbal Allograft) is an eye reconstruction surgical procedure that involves transplanting tissue taken from the normal healthy eye of a living donor.

The limbal stem cells are found around the cornea (the clear dome that covers the colored iris of the eye).



Symptoms of Limbal Stem Cell Deficiency

- Trouble seeing
- Eye pain, redness or tearing that does not go away
- A feeling that you have something in your eye
- Light sensitivity (bothered by bright light)

What are the benefits of having this operation?

After having this operation, the outer layer of the cornea should grow back normally, and your symptoms should get better.

We will help you understand the benefits and risks of having a transplant. This will give you the information to make an informed decision. **The decision to proceed is up to you.** We will support your choice whether you choose to go forward with limbal allograft transplantation or not.

Am I Eligible for a Limbal Allograft Transplant?

Each patient is assessed individually for their suitability for transplant. Basic requirements for limbal allograft transplant are:

1. Your transplant assessment shows that you:
 - a) Have limbal stem cell disease that will not improve without transplant
 - b) Are able to safely tolerate surgery and post transplant immunosuppression medications
2. You want to have a transplant, and you understand and accept the responsibilities required before and after transplant.

Our goal is to make your transplant as safe and as successful as possible. Our commitment to you includes involving you in your care decisions, helping you to understand your treatments and checking with you regularly to ensure that your treatment plan is working.

We will need your commitment too. **Having a transplant will change your life significantly.** Before you make this choice you need to be prepared to make many changes. After your transplant you must follow the treatment plan carefully to have a successful transplant. This includes being part of your health care team, learning about your treatments, taking your medications and attending your clinic appointments.

Advantages & Disadvantages of Limbal Allograft Transplant

Advantages:

- Improved vision
- Decreased Pain

Disadvantages:

- You will need transplant medication (immunosuppressants and others) for as long as your transplant is functioning to prevent rejection.
- You will need follow-up transplant care for as long as your transplant is functioning.
- You may have side effects from your medications
- You will be at greater risk for infection and diabetes after transplant
- You will be at greater risk for certain types of cancer

Infection Risks with Transplantation

The risk of infection related to transplantation needs to be considered when choosing whether or not to proceed with limb allograft transplantation. We hope this helps transplant candidates make an informed decision about transplant surgery. Please speak to your doctor or transplant coordinator if you have **any** questions about the information that follows below. It is important to understand that most patients do not develop serious infections after transplant, but the risk is higher.

Infections are an unavoidable risk of transplantation. They are the most common complication after transplantation, occurring in about 1/3 of patients. The risks of developing an infection must be balanced against the benefits of a transplant.

Transplant patients are at greater risk for infection because the anti-rejection drugs given after transplant affect their immune systems. Bacteria, viruses, fungi, or other organisms can cause infections. Most infections can be successfully treated, but some are difficult to treat and can cause disability or death.

We try to minimize the risk and impact of infections in part by

- 1) routine testing of the donor and of blood products;
- 2) giving anti-infective medications at the time of surgery and sometimes afterwards; and
- 3) monitoring and testing recipients.

Our knowledge of the infection risk with transplantation continues to grow. Over time, we will continue to learn about new infections that are currently unknown. Some, but not all, of the infection risks associated with transplantation are discussed below.

Multi-drug Resistant Bacteria

Some patients in hospital have developed bacterial infections that are resistant to standard antibiotics. Some specialized antibiotics may be effective in this situation. We try to reduce the risk of multi-drug resistant bacterial infections in our transplant unit by only giving antibiotics when absolutely necessary.

Viral Hepatitis (Hepatitis B, C)

Donors are tested for the presence of hepatitis B and C virus infections. As with other viral infections, testing is accurate but not 100% effective in avoiding disease transmission. The risk however is small. Organs and tissues from donors who have been exposed to the hepatitis B or C virus are sometimes knowingly given to recipients who have also been previously exposed to, are already infected with this virus or have developed immunity.

Cytomegalovirus (CMV)

CMV can cause flu-like symptoms, pneumonia, hepatitis, and other illness. Most people have already been exposed to this virus and have some degree of immunity. Since CMV is very common in the general population, you may receive tissue from a donor that is positive for CMV. Most transplant recipients are at risk of developing CMV infection and thus will be given prophylactic medications to reduce the risks of CMV infection. Reasonably effective treatment is available if a CMV infection develops or recurs post-transplantation.

Epstein - Barr virus (EBV)

EBV also causes flu-like symptoms and infectious mononucleosis. Rarely, it can cause a disease similar to a lymphoma (a type of blood cancer). Fortunately, most people have been exposed to EBV and have partial immunity. If you are at increased risk for this infection, your doctor will discuss it with you.

West-Nile Virus

Most patients with this infection have no symptoms or minor symptoms. Sometimes the infection can produce permanent brain or nerve damage. This virus is transmitted by insect bites, but also through blood transfusions, organ or tissue transplantation. It is a fairly new problem in Ontario. We do not yet know the likelihood of contracting this infection but a very small number of our organ transplant recipients have become infected. Although some have recovered, others have become disabled or have died. Currently blood, tissue and organs from donors with symptoms suspicious for recent West-Nile infection are excluded.

AIDS (Human Immune Deficiency Virus)

All donors are tested for HIV. The testing is very accurate but again not 100% reliable for preventing HIV transmission with blood, organ and tissue donation. There is a brief period of time during the beginning of an HIV infection when the virus testing could be negative but the donor could still be infectious. The risk of transmission is very small, but not zero.

Unknown Infections

Transplant recipients may be at risk of acquiring previously unknown infections due to their weakened immune system. It is possible such an infection may be acquired from the donor. Every effort is made to ensure that donors with symptoms suspicious for any type of known or unknown infection are excluded.

See *Appendix 4* for recommended vaccinations

The Transplant Assessment Process

The transplant assessment process helps to determine if you are a transplant candidate. An important part of this assessment is to try to ensure that you can tolerate the physical and emotional stress of the operation and the post-operative recovery. During your initial assessment for limbal allograft transplant, you will meet with many of the health care team members who will help decide if transplantation is the right option for you.

Sometimes your assessment will uncover a problem that makes transplantation a poor option for you. It could also identify a problem that needs to be corrected before you become a candidate for a limbal allograft transplant.

Your assessment includes extensive medical tests and interviews with members of the transplant team. We try to make sure that you do not have any other conditions or health problems that would put you at too high a risk for a limbal allograft transplant.

The Transplant Work-Up

Several tests are routinely done during assessment. These may include:

1. **Blood work** (to help us ensure there are no underlying medical issues and to help match you with your potential donor)
2. **Chest X-ray** (to look at your lungs, diaphragm, and heart size)
3. **ECG** (Electrocardiogram) (an electrical picture of your heart)
4. **Echocardiogram** (an ultrasound of your heart)
5. **Exercise or Persantine Stress test** (a test to determine how your heart performs)
6. **Abdominal Ultrasound** (to help us ensure there are no underlying medical issues)
7. **Urine Tests** (to provide information about your kidneys)

Other tests may be required if we become aware of a problem.

Consultation Interviews

As part of the assessment process, interviews will be arranged with several members of the transplant team. They may include:

- Ophthalmologist
- Nephrologist
- Social Worker
- Psychiatrist or Psychiatric Nurse
- Cardiologist
- Respiriologist
- Transplant Coordinator
- Oncologist

Living Donor Limbal Allograft Transplant (CLAL)

Benefits of Living Donor Transplant

- the recipient receives a high quality tissue with excellent graft function
- decreased recipient waiting time for limbal allograft transplant
- higher success rates for recipient
- the donor can help improve the eye health for a close friend or family member.

Disadvantages of Living Donor Transplantation

- placing an otherwise healthy individual (the donor) at a very minor risk

Living donors can be a friend or relative in good health, with a compatible blood type. If there is someone you know who is interested in learning about living donation, ask them to call or visit the website for more information.

Limbal Allograft Transplant Office 416-340-4800 Ext 6707

www.UHNtransplant.ca

Living Donor Assessment

Potential donors have a thorough evaluation by the health care team. They undergo a series of blood tests, x-rays and consultations with specialists to provide information about the procedure.

- Donors must be in excellent physical and emotional health.
- Donors cannot have any history of cancer, or any active infection at the time of donation.
- Donors must have a normal eye exam.
- Donors should have family and friends who can provide support before, during and after surgery.

Principles Guiding Living Donor Selection

- ✓ Living donor must be older than 16 years of age
- ✓ Living donation must be voluntary and benevolent
- ✓ Donor safety is the priority during assessment & donation
- ✓ Any newly found donor health issues will be addressed in consultation with the donor's family doctor
- ✓ The donor should communicate with the transplant team if there are any concerns during the assessment process
- ✓ OHIP pays for the entire costs of the operation & hospital care

- ✓ Costs for time lost from work, travel, etc are not compensated by the hospital or OHIP. (Some costs may be reimbursed by the government. Speak to your donor coordinator or social worker for more details)

Matching Donor and Recipient

To match a limbal allograft donor with a recipient, the donor must have a compatible blood type. The table below shows compatibility.

If your Blood Type is	You can RECEIVE a transplant from blood type:	You can DONATE to a patient with blood type:
O	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	O, A, B, AB	AB

******In approximately 5% of live donor cases we have needed to cancel scheduled surgery within 1 or 2 days prior. This is due to additional findings and concerns that arise from a final team review of both the donor and recipient charts. This last minute cancellation can be disappointing and frustrating for both the donor and recipient. Our primary focus when offering live donor transplantation is the safety of our patients. Due to the intense nature of donor and recipient assessments, as well as ongoing surveillance, new findings may develop and result in the team deciding that it is no longer safe to proceed with surgery.******

Considerations for Living Donor Limbal Allograft Transplantation Recipients

- ✓ Recipient must be suitable for living donor graft
- ✓ Recipient agrees to living donor transplant
- ✓ Recipients agree that the program can provide donors with information regarding the cause of the recipient's underlying disease, the potential for success and chance for success post-transplant

The Costs of Transplant Medications

- When you are discharged from the hospital after your transplant, you must be ready to pay for your medications.
- These costs may be as high as \$2,000 per month.
- If you have not registered with Trillium and paid the deductible, you will need to pay by:
 - Using your drug benefit card to directly bill your insurance company (if your company offers this option)
 - VISA or MasterCard
 - Cash
- The Transplant Unit will **not** provide you with medications to take home.
- Toronto General Hospital **does not** have a drug assistance plan for Transplant patients.

Drug Coverage – Private Insurance

- Who is the provider of your private drug coverage (i.e. Sunlife, Manulife, etc.)?
- What is the percentage of medication costs covered by your private insurance?
- Is payment of medications automatic or do you have to pay up-front and get reimbursed later?
- Are there any yearly maximums for drug coverage?
- Are there any lifetime maximums for drug coverage?
- If you pay for your medications up front, how do you plan to pay for your transplant medications? **YOU MUST HAVE A PAYMENT PLAN IN PLACE PRIOR TO TRANSPLANT!!**
 - You should submit a medication list to your insurance company for pre-approval. You can request this list from your social worker or transplant coordinator

**** REGARDLESS OF DRUG COVERAGE THROUGH PRIVATE INSURANCE, YOU ARE STRONGLY ENCOURAGED TO HAVE ONTARIO DRUG BENEFIT (ODB) COVERAGE – TRILLIUM, SENIORS BENEFITS, OW/ODSP – IN PLACE****

- If your transplant team needs to request special approval for medications that your private plan does not pay for, we can only do so with ODB in place; therefore, advanced application and approval to these programs will prevent any delays in providing unexpected treatments.

The Trillium Drug Program

Many transplant drugs are expensive and unusual. These drugs can cost hundreds or thousands of dollars each month. Even the best insurance programs may not completely cover the costs of these medications. The Trillium Drug Program, funded by the Ontario Government, is available to all Ontario residents to help pay for such medications.

*All patients should be registered
with the Trillium Drug Program before being
scheduled for their transplant.*

There is no cost to register with Trillium. The application takes only a few minutes to complete. Being registered with Trillium does not interfere with your private drug coverage. Patients with private coverage can still use this program. You can apply to Trillium for assistance with drug costs that are not covered or only partially covered by your private drug benefit plan. You can get applications at the pharmacy, online, or through our social workers.

As a transplant patient, you must keep your registration active with Trillium.

You must ensure renewal every year prior to August whether you are a pre- or post-transplant patient.

What is the Trillium Drug Program?

The Trillium Drug Program is an Ontario government program that helps people pay for their prescription drug costs. You can apply to Trillium if you have private insurance that pays for a portion of your medication, or if you are without a drug plan.

How does the program work?

People who use the program are required to pay a yearly deductible. Trillium's program year runs from August 1st to July 31st. You can join partway through a program year and sometimes you can back date your enrolment.

The deductible is based on the number of people in your household and your total household net income. The program year is divided into four quarters (starting August 1st, November 1st, February 1st, and May 1st), so you don't have to pay your whole deductible at once. In each quarter, you will only pay one quarter of your household's total deductible before Trillium will pay for the rest.

For example, a household with two adults and one child with a total net income of \$40,000 will have a yearly deductible of about \$1,300.00. In each quarter they will have to pay \$325.00 in prescription drug costs before Trillium will pay for the rest.

The program only covers prescription drugs that are listed on the Ontario Drug Benefits (ODB) list of covered drugs, which does not include all of the drugs your Doctor may prescribe.

Who can apply?

You can apply to the Trillium Drug Program if:

1. you reside in Ontario and have a valid Ontario Health Insurance (OHIP) Card, and
2. you are under age 65

How do I apply?

Application forms and program guides are available at most drug stores, or you can find them online at: <http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>. You must complete the application in full and include proof of income for each household member. You can send receipts for prescriptions you may have already paid for, if you are applying partway through a program year, as this can be counted towards your yearly deductible (remember to back date your enrollment). If you have no previous out of pocket drug costs, then you can use the current date as your enrollment date and your deductible may be less as it is prorated after August 1st. You will receive a letter within 3-5 weeks confirming you are accepted to the program, and how much your household's yearly deductible will be. Once you are registered with the program, you will need to use your OHIP card when filling your prescriptions at the drug store.

What if I have more questions?

Contact Trillium directly at:

Address:	Phone (24 hours):	Fax:	Email:
PO Box 337, Station D Etobicoke, ON M9A 4X3	Toronto: 416-642-3038 Toll Free: 1-800-575-5386	416-642-3034	trillium@resolve.com

If you need urgent drug coverage, please speak with a Social Worker.

Financial Information

Having a transplant can have an impact on your finances. It is important for you to know this and plan ahead. Your income may change and you may have new expenses. Every situation is unique. Use the following information as a guide to see if there are opportunities for financial support. See *Appendix 2* for resource contact information.

Transplant patients may be eligible for financial help from sources such as:

- Insurance – Employment or Sickness benefits
- Employment and retraining funding
- Canada Pension Plan - Disability (CPP-D)
- Ontario Works (OW)
- Ontario Disability Support Program (ODSP)

It is important to know how these programs may assist you with important financial support. Please contact your transplant social worker for assistance and details about these programs to see which ones you may qualify for.

Insurance

a. Employment Benefits

Some transplant patients are able to return to the job or position they had before transplant. Depending on your employer and the amount of time you are off sick, you may have **short or long term disability (STD or LTD)** benefits. Your employer will be able to tell you more about this.

b. Sickness Benefits

If your work does not have STD/LTD or the payment is low, you might qualify for Employment Insurance (EI) sickness benefits. EI sickness benefit gives you 15 weeks of income. Contact your local EI office for more information about qualifying.

Employment and Retraining Funding

Some patients may return to work after transplant but need to change their job. In this case, patients may qualify for an Ontario government program for vocational assessment and rehabilitation. This program is for patients who have physical problems that prevent them from finding or keeping their job.

Unfortunately, there is a long waiting list. Once you are accepted into the program, you qualify for financial assistance for retraining costs and a living allowance.

Private companies also offer vocational assessments, counseling and retraining for a fee. Some community agencies offer counseling free of charge or for a small fee.

Canada Pension Plan - Disability (CPP-D)

If you are permanently unable to work after your transplant and you paid into CPP, you can apply for CPP benefits. CPP approves your application based on the medical information that they receive from your doctor. Drug benefits are not included.

Fill out an application as soon as possible. It can take several weeks to process. Benefits are not retroactive. Some restrictions may apply.

Ontario Works Assistance

You can apply for Ontario Works (OW) if you have a low income, few assets and are temporarily not able to work. Your total family income determines if you are eligible. Drug benefits are included. You will have to contact your local OW office for assessment.

Ontario Disability Support Program

If your doctor states you are permanently disabled and cannot return to work, you may qualify for the Ontario Disability Support Program (ODSP). This program is also for patients with low family income and few assets. Drug benefits are included. You will have to contact your local ODSP office for assessment.

Other Financial Considerations

Before and after your transplant, you will have expenses related to doctor and clinic visits. These will be out of pocket expenses. We will describe a few below and offer some brief tax tips to help you recover some of these costs.

Parking

Parking near the hospital is expensive. The closer to the hospital you park, the more expensive it is. There are some parking lots a short walk from the hospital. It is worth looking at the costs of nearby lots if you will be coming to the hospital often. Consider taking public transit (TTC) or Go Transit whenever possible.

Shuttle Bus

University Health Network offers shuttle buses between Toronto Western Hospital and Toronto General Hospital. Shuttle buses leave Toronto General Hospital from University Ave, and leave Toronto Western Hospital from Leonard Street Entrance, entrance every 15 mins. This is a FREE shuttle and takes about 15 mins to get to Toronto Western Hospital.

Wheel Trans

If you live in Toronto and are physically disabled, you can apply for Wheel Trans. This service is available to people who are not mobile enough to use the regular transit system.

To get a Wheel Trans number, you must have an interview with the TTC. Call (416) 393 – 4111 to set up an appointment. They may supply transportation to the interview appointment if you are in a wheelchair or use a cane or walker to move around.

Travel

For patients living in northern Ontario, the Northern Health Travel Grant provides some financial assistance for travel to medical appointments. As a patient, you must pay the cost of travel and then apply for reimbursement.

You will need to have your local doctor fill out their section of the travel grant form, and then bring this form to your transplant specialist to fill out their section.

Social assistance (OW/ODSP) may help you with travel costs, no matter where you live. You must apply at your local office for help.

Hope Air may offer fares at a reduced rate for patients who live outside Toronto. This is **NOT** an air ambulance service. You will need to book 2 weeks in advance of your appointment.

Toll free: 1-877-346-HOPE (4673)

Toronto area: 416-222-6335

www.hopeair.org/

Other Costs

There will be other costs during your transplant. You may need to buy special supplies that are not covered by private insurance plans. For example, if you become diabetic, you will need equipment that may not be covered.

Some support services may require documentation in order to offer reduced rates. Talk to your social worker or transplant coordinator about this.

Tax Tips

Call Revenue Canada for information about deductions on your income taxes related to your illness and your transplant.

Here is a recent list that may be helpful. Remember you must have receipts for all your expenses. You **cannot** claim for anything that you have already received re-imbusement for.

Medical expenses that you **may** be able to claim include:

- long distance telephone calls to the hospital
- any diagnostic procedures where you had to pay
- payments to hospitals
- drugs that you paid for yourself
- premiums for private health service plans
- ambulances
- parking
- Out of Canada medical expenses – for the part that OHIP did not cover.

You may claim expenses for yourself, your spouse and, with some limitations, your dependants. You can claim expenses for any twelve-month period ending in the current year.

- If you travel more than 40 km one way for treatment, you may be able to claim transportation costs: train, bus or taxi costs.
- If you used your own car, you can claim a reasonable amount (check with Revenue Canada). You will need to prove the number of trips you made. Keep a travel log with mileage that you traveled. Have your health care provider sign and date it each time you come to the hospital.
- If you travel more than 80 km one way, you are entitled to claim reasonable expenses for meals and accommodation as well.

Disability Credit

If you are disabled, as defined by Revenue Canada, you can ask your doctor to fill out a disability tax credit. Include this in your tax return.

You **may** qualify for a disability credit for the cost of care for a nursing home stay or a full-time attendant.

Please note: Many transplant patients do not qualify as disabled within the Revenue Canada definition.

If you have any questions about these topics, please speak to your social worker

Legal Information for Patients

Powers of Attorney

It is important that you think about your situation and make plans for your powers of attorney. There are two basic forms of Powers of Attorney (PoA):

- Powers of Attorney for Personal Care
- Powers of Attorney for Finances

Powers of Attorney for Personal Care

Your power of attorney (PoA) for personal care is a person that you choose to make decisions about your care when you are not able to make them yourself. This person is also called your Substitute Decision Maker (SDM).

To appoint a PoA, you need to create a legal document called *Powers of Attorney for Personal Care* decisions.

If you do not assign a PoA for personal care, the law states who can make decisions, in the following order of priority:

- spouse
- adult children
- parents
- siblings
- extended family members.

If there is no one to make decisions for you, the law states a public official can be appointed to make decisions for you when you cannot.

Sometimes patients have a PoA for health care decisions that is different than their usual substitute decision maker. If this applies to you, make sure this is clearly stated in your PoA document.

Give copies of your PoA document to your doctor, your social worker and your PoA .

Powers of Attorney for Property

Your power of attorney for property is a person that you choose to make decisions about your finances when you are not able to make them yourself.

To appoint a PoA for Property, you need to create a legal document called Powers of Attorney for Property.

This legal document states who will be responsible for making financial decisions, payments, etc., if you are unable to do so.

*Powers of Attorney are powerful documents.
They impact on your care and your finances.
It is a good idea to get legal advice to set up your Power of Attorney*

Advance Care Planning

Advance Care Planning is also known as advance directives and living wills.

Decisions about your healthcare need to reflect your wishes and values. There may be a time in the future when you are unable to make decisions about your medical care and treatment. This situation may be temporary or permanent; it could happen suddenly or gradually. If you were unable to make decisions for yourself, there are two important things we need to know:

1. What are your specific wishes regarding your healthcare?
2. Who would you want to make decisions for you?

It is important to answer these questions now, while you are capable of making decisions. This helps to ensure that **your** wishes will guide your care.

Advance care planning helps to clarify how you wish to be cared for and gives someone you trust the authority to act on your wishes. This person is also known as a Substitute Decision Maker. This is the only person we would ask to make decisions, in the event that you are unable to do so.

Please talk about your care wishes with your family and anyone else who might make decisions for you in the future. We are always happy to answer any questions you have about advance care planning.

There are guides that you can use to help you with Advance Care Planning:

<http://www.citizenship.gov.on.ca/seniors/english/programs/advancedcare/docs/AdvancedCare.Guide.pdf>

After the Assessment Process

Once the tests and consults are finished, the transplant team will meet to review the results. If there are no contraindications and you are prepared to go forward, we will discuss proceeding with surgery. Whether you receive tissue from a deceased donor or a live donor, we will schedule an OR date.

A meeting will be scheduled for you with the Ophthalmologist who will perform your surgery a few weeks before the OR date. He/She will review information with you and your family about the transplant surgery. The successes and risks of limbal allograft transplant will also be discussed.

Maintaining Contact with the Transplant Team While Waiting

We must know how to contact you at all times. For this reason you need to provide your assessment coordinator with all of your contact information:

- Home phone number & address
- Work phone number (if applicable)
- Cell phone number
- A nearby friend or relative

Please keep your contact information up to date at all times.

You must inform your coordinator immediately if:

- Any of these contact numbers change
- You will be out of reach for a period of time (e.g. travel)
(be sure to leave a telephone number where you can be reached while you are away if applicable).
- You are admitted to another hospital

Coping with Stress

We do not know how long you will need to wait for transplant, but will continue to communicate with you as we work towards a date for surgery. This can be stressful and discouraging for you, your family and your support network. Feelings such as fear, impatience, even anger are normal.

During your assessment you will meet some of the Psychosocial Team members. They are:

- Social Workers
- Psychiatric Nurses
- Medical Psychiatrists

Our team offers:

- Education and information before and after your transplant.
- Help with financial and family matters
- Counseling and emotional support, both for you and your support persons

It is important for you to talk to someone. Telling us about your feelings, getting help to put your concerns in perspective and relieving your stress can help you feel in control.

The Deceased Donor Process

If a living donor limbal allograft transplant is not an option for you, you must wait for tissue from a deceased donor.

Tissue donation within Canada is based on the kindness and generosity of the donor family consenting to donate a loved one's organs and tissues, at the time of their death. The continued success of transplantation hinges on organ and tissue donation.

The waiting list is made up of people throughout Ontario who are waiting for donor tissue. **Eye Bank of Ontario** is the organization that takes care of the retrieval and preparation of ocular tissue in Ontario. They organize the tissue donation process with Trillium Gift of Life Network (TGLN) and transplant centers.

- Once a potential organ and/or tissue donor is identified, the next of kin is asked to consent for organ donation.
- The organ and/or tissue donor is tested to make sure the organs and/or tissues are suitable for transplant. Tests include blood tests, virus tests (such as HIV, Hepatitis B & C), x-rays and scans.
- After the eye surgeon accepts the organ and/or tissue, the donor is taken to the operating room. A specialized team of surgeons then works carefully to remove the organs and/or tissues for donation.
 - The donor eye is stored in a special storage media and transported to the operating room.

The wait time for a donor eye can vary from a few months to around a year. This can be a very stressful and discouraging time for you.

Waiting for transplantation can be a difficult time. There are many resources available to help you deal with this stress. A good place to start is with the members of your transplant team.

Preparing for Limbal Allograft Transplant

On the Night Before Your transplant:

- Do not eat any food or drink any fluids after midnight (this includes no chewing gum or candy)
- You can drink clear liquids, such as water, apple juice, clear tea or coffee (**with no milk or cream**) up to 5 hours before your surgery.
- You may rinse your mouth and brush your teeth
- **Do not smoke** for 5 hours before your surgery
- **Do not drink any alcohol** for at least 24 hours before your surgery.
- **Stop Aspirin and any blood thinners 5 days prior to surgery**

Remove:


- All nail polish (from your fingers and toes)
- All jewelry and body piercings. (if it is not removed, your operation may be cancelled)
- Leave all jewelry at home, even Medical Alert chains (write this information down and give it to the nurse when you arrive)
- All makeup
- Contact lenses (wear your glasses to the hospital)
- Leave all valuables at home, bring only a small amount of money to the hospital (The hospital is not responsible for lost or stolen items)

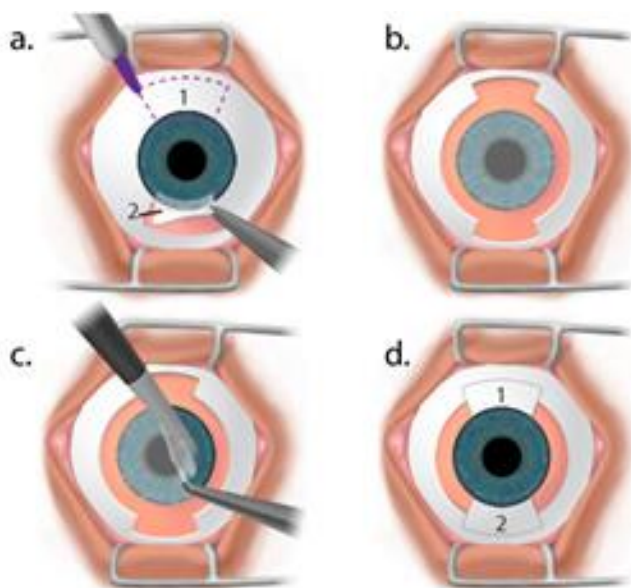
What to Bring to the hospital:

- Health card
- Blue Hospital card
- All medications you are presently taking, in their original bottles
- Wear loose-fitting clothes and flat shoes
- Hearing aids, dentures and glasses can be worn, but may need to be removed for your operation.

On the Day of Your Operation:

- Please arrive at the Toronto Western Hospital at the time written in your package. (You should receive a package in the mail approximately 1 month before the day of your operation).
- In the pre-operative waiting room area, a nurse will put an IV into your arm and check your blood pressure, temperature, pulse and breathing rate.
- The anesthesia doctor or assistant will speak to you about the type of anesthesia you will have (usually local only).
- We will transfer you to the operating room. We give you medication through the IV to help relax.

- We give you eye drops to completely numb (freeze) the eye which will be providing the donor tissue.
- Your ophthalmologist will take 2 small pieces of tissue from the donors' eyes that are about 6 mm by 4 mm. Or, about this size  This tissue has the limbal stem cells. The tissue is stored in a special solution for the recipient's operation.
- The surgeon closes the wounds with a few stitches or tissue glue and puts antibiotic drops into the eye. The donor may need to wear an eye patch for a few hours or overnight.
- For the recipient's operation, the ophthalmologist will remove any scar tissue over the surface of the cornea.
- Then using a few stitches and/or tissue glue, the ophthalmologist secures the small pieces of donated tissue with the limbal stem cells.
- The surgeon closes the wounds with a few stitches or tissue glue and puts antibiotic drops into the eye. You may need to wear an eye patch for a few hours or overnight



- The donor may experience pain overnight, and may last up to 3-4 days. Pain medication will be prescribed. The pain will completely resolve a few days following surgery. The eye will also be read for 1-3 weeks. This too resolves on its own and does not require additional treatment.

Post-Transplant Information and Requirements

The following information relates to post-transplant requirements:

- Your ophthalmologist will examine your operated eye the day after your transplant. It is normal for the eye to be red, feel scratchy or burn, have blurry vision, increased tearing and some eyelid swelling.
- One (1) to two (2) weeks after your transplant your ophthalmologist will give you instruction about when you can stop taking your eye drops.
- You will have clinic visits + blood work at University Health Network 1x/week for two (2) to four (4) weeks after you are discharged from hospital;
- You will have blood work 1x/month close to home for six(6) to eight(8) weeks after you are discharged from hospital;
- You will then have bloodwork every three (3) months unless otherwise instructed by your coordinator.
- There may be unscheduled clinic visits at Toronto General Hospital, as needed, based on blood work results;
- Attendance by a support person for clinic visits is required, as changes to medications and information sharing occurs;
- You will need someone to bring you to the hospital for your clinic appointments, as you will be unable to drive for three months from the time of your transplant. You may choose to rely on volunteer drivers or a taxi for these visits, but a support person's attendance is still required. Any out-of-pocket costs associated with transportation will be your responsibility (unless you are in receipt of government assistance that covers these types of medical-related costs).
- You will need to ensure that you have adequate financial resources to manage the costs of transplant, including return visits to hospital and drug costs (i.e. Trillium Drug Program deductible; private insurance co-payments, pharmacy dispensing fees, etc.);
- You may need/choose to relocate to Toronto for a period of one (1) to three (3) days after you leave hospital. Any out-of-pocket costs associated with relocation will be your responsibility (unless you are in receipt of government assistance that covers these types of medical-related costs).
- You need to ensure you have adequate and guaranteed drug coverage. This will be discussed in more detail towards the end of your transplant evaluation, but is a requirement for transplant suitability.

A patient's inability to meet the above stated transplant requirements may deem them unsuitable to proceed with transplant. Once you have completed the medical portion of your transplant evaluation, you will be scheduled to see a social worker who will discuss these requirements in greater detail based on your personal needs. Please ensure a support person attends your social work appointment with you.

Your Transplant Medication

Monitoring for infection and rejection is our first priority in making sure your new tissue is working well. Frequent blood work and other assessments will show if it is working properly.

A rejection episode happens when your body's immune system recognizes your new tissue as foreign. The body will try to react against your new tissue and this process can damage your new stem cells. Blood tests and eye exams monitor for changes that may be a sign of rejection. Identifying the early signs of rejection is important so that this process can be stopped and your new tissue can continue to work well for you.

Your ophthalmologist and transplant team will monitor and treat early signs of rejection, and may adjust your medication and therapy. We will teach you the signs and symptoms of rejection so that you know what to watch for at home.

Adjusting your Immunosuppressive Medications

Two weeks before your transplant, you will start taking immunosuppressive drugs. These stop your immune system from rejecting your new tissue. It is important that we have you on the right doses of these drugs. You may have many changes in your drugs until we find the right levels for you.

We will adjust your medication dose based on:

- Blood test results
- Side effects of medication
- Symptoms
- Eye exam findings

The Transplant Pharmacy Website

There is a lot of new information to learn and process around the time of transplant. Important questions about the transplant medications may arise before transplant, while in hospital, and even long after a transplant. Your Transplant Pharmacist will answer these questions and assist you in learning about your new medications while you are in the hospital. We have also developed some online programs and tools that can be accessed at any time on the UHN public internet site that will help you learn more about your transplant medications.

The **Transplant Pharmacy website** is located on the UHN public Internet site. To visit the website, please follow these instructions:

1. Go to www.UHN.ca
2. Click on the "Focus on Care" link on the left side of the page
3. Click on the "Multi-Organ Transplant" link
4. Click on the "Transplant Pharmacy" link on the right side of the page

Or, you can type the address for the Transplant Pharmacy homepage directly into the address bar of your web browser: http://www.uhn.ca/Focus_of_Care/MOT/Transplant_Pharmacy/index.asp

On the website you will find answers to Frequently Asked Questions regarding *Managing Your Medications* and *Life After Transplant*. You can also watch a short video entitled *Your Transplant Pharmacist: Caring for Your Medication Needs During Your Hospital Stay*. This video will describe some of the services you can expect from your Transplant Pharmacist while you are in the hospital. In the *Patient Toolbox* area you can access information regarding prescription drug coverage and download log sheets to help you manage common medical conditions such as high blood pressure or high blood glucose.

Transplant Medication Information Teaching Tool (TMITT)

The Transplant Medication Information Teaching Tool (TMITT) is an interactive internet-based teaching program to help you and your family or support person learn more about your transplant medications. This tool is flexible and designed to allow you to learn at your own pace by selecting the specific medications and material you want to learn about.

Some of the features include:

- Content that is divided into brief and easy to follow ‘lessons’
- Ability to customize your own learning experience
- Unique audio-visual format
- Interactive quiz questions to test your knowledge
- Printable information summaries for each medication

The TMITT program can be launched through the Transplant Pharmacy website. To access this tool you may click on the link that is displayed on the right side of any page. You can also go directly to this program by visiting www.TMITT.ca.

Common Post-Transplant Medications

Information on common post-transplant medications can be found in *Appendix 1* at the back of the manual. Please refer to these information sheets for details regarding your specific medications. These are medications that *may* be prescribed for you after transplant. You may also need to take other medications that are not discussed in this manual.

You may not be taking all of the medications listed here. Your transplant team will choose the combination of medications that is best for you. You may also be prescribed other medications to prevent or manage side effects from the anti-rejection drugs. Medications to treat common conditions such as high blood pressure, osteoporosis, and diabetes are not described here.

While Taking Immunosuppressive Drugs

Side effects from medications are common, especially right after your transplant. Your body is adjusting to the new tissue, as well as many new medications. Everybody responds differently to the medications. It will take time for your transplant team to establish the right drug combination and doses for you.

During the first day or two after transplant surgery, it is normal for recipients to:

- be tired
- be confused and disoriented
- have difficulty concentrating, and
- have difficulty sleeping

It is important to remember that your transplant team expects these side effects and are trained to deal with them. Adjusting your medications or adding another drug may help to reduce side effects. Talk to your transplant team if you have questions or concerns about your symptoms.

Drug Interactions

Many drugs can interact with your transplant medications. Before you take any new medications, including any over-the-counter products or medications prescribed by a non-transplant doctor, you **MUST** talk to your transplant team. For example, some antibiotics, non-prescription cold medications, or herbal remedies can interact with your transplant medications to cause unwanted effects.

If you would like to take a multi-vitamin or any herbal remedy (including herbal teas), please talk to your transplant team first. Herbal remedies are like drugs and may interfere with your medications so proper precautions need to be taken.

Pain Medications

Do not take pain relief medications known as NSAIDs (non-steroidal anti-inflammatory drugs). This includes ibuprofen (the active ingredient in Advil® and Motrin® products); naproxen, which is found in Aleve® and Naprosyn®; and also ASA or Aspirin®. If you are taking an 81mg 'baby' Aspirin® once daily to prevent heart attack and stroke, this is okay if it is on the advice of a doctor. If you need to take medication for pain or a headache, acetaminophen (**Tylenol**®) is usually a safe choice. Talk to your transplant team before taking any other pain medication.

Appendix 1

PROGRAF® (tacrolimus immediate release)		
GENERIC NAME	BRAND NAME	REASON FOR USE
Tacrolimus immediate release Strengths: 0.5 mg, 1 mg and 5 mg capsules	PROGRAF®	Tacrolimus is an anti-rejection drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted tissue.

SIDE EFFECTS

- 1. INCREASED BLOOD PRESSURE** Your blood pressure will be monitored. You may require treatment with blood pressure medications.
- 2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM** This can include trembling hands, headaches, mood changes and trouble sleeping. This is usually related to the level of Prograf in the blood and usually subsides with time as blood levels are decreased.
- 3. HARMFUL EFFECTS ON THE KIDNEY** The level of Prograf® in your blood will be closely monitored and the dose will be adjusted if needed. Your kidney function will be monitored with a blood test called creatinine.
- 4. GASTROINTESTINAL UPSET** This may include stomach upset and diarrhea. The degree to which this occurs is variable and will depend on how your body reacts with the medication.
- 5. DIABETES (Increased blood sugar)** Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.
- 6. INCREASED SUSCEPTIBILITY TO INFECTION** Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.
- 7. INCREASED RISK OF DEVELOPING CANCER** The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

PROGRAF® (tacrolimus immediate release)

DOSAGE ADJUSTMENTS

You will be advised to adjust your dose up or down based on the amount of Prograf® in your blood. Blood tests are done just before your morning dose. On the days you are having bloodwork, always remember to **delay your morning dose of Prograf® until after your blood is drawn**. Changes in dose are common so always check with your transplant team if you are unsure of your current dose.

STORAGE

Keep at room temperature. Do not expose Prograf® to extremes of temperature (direct sunlight or refrigeration).

INTERACTIONS WITH OTHER MEDICATIONS

- Many medications can change the level of Prograf® in your blood. This may cause serious problems.
- Do not take **any** medications, including non-prescription drugs or prescriptions (given to you by anyone other than your transplant doctors), without first contacting your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase Prograf® blood levels.

REMEMBER Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

TAKING YOUR MEDICATION

- Prograf® (tacrolimus immediate release) is taken twice daily every 12 hours, *e.g.* 9:00 am and 9:00 pm. This is to ensure that you maintain a consistent amount of drug in your body. Always take your doses at the same times every day
- Always be consistent with respect to Prograf® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Avoid grapefruit and grapefruit juice as these can increase Prograf® blood levels.
- Do not get this medication confused with Advagraf® (tacrolimus extended release), which is a once-daily formulation of tacrolimus.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

PREDNISONE

GENERIC NAME	REASON FOR USE
Prednisone Strengths: 5 mg and 50 mg tablets	Prednisone is a cortisone-like anti-rejection drug. This medication works to suppress your immune system in order to prevent rejection of your transplanted tissue.

SIDE EFFECTS

- 1. STOMACH UPSET OR IRRITATION** Take prednisone with food or milk. An acid-reducing medication may be prescribed. Report any severe symptoms or blood in your bowel movements to a doctor right away
- 2. WATER RETENTION** May cause swelling of the face, ankles or hands. You may need to restrict salt in your diet. A diuretic ('water pill') may be prescribed. This effect usually subsides as the dose is reduced.
- 3. FACIAL PUFFINESS** More common with higher doses. This usually subsides as the dose is reduced.
- 4. INCREASED APPETITE** Weight gain may occur if you overeat.
- 5. DIABETES (Increased blood sugar)** Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.
- 6. SLEEP DISTURBANCES, NIGHTMARES, MOOD CHANGES** Take prednisone in the morning to minimize the effect on your sleep. These effects usually subside as the dose is reduced.
- 7. BRUISING** Your blood vessels may become more fragile which can cause easy bruising. Try to protect yourself from injury.
- 8. OSTEOPOROSIS (Thinning of the bones)** Your bones may become weaker which can increase your risk of fractures. You may be advised to increase calcium in your diet, do a weight-bearing exercise such as walking, or take calcium supplements or other medications to increase bone density.
- 9. INCREASED SUSCEPTIBILITY TO INFECTION** Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.
- 10. OTHER SIDE EFFECTS MAY INCLUDE** Increased hair growth, acne, cataracts, or menstrual irregularities.

PREDNISON

TAKING YOUR MEDICATION

Prednisone is taken once daily in the morning.

Prednisone should be taken with food or milk to prevent stomach irritation.

The dose prescribed may be any combination of 5 mg tablets or half tablets.

Examples: 20 mg = 4 of the 5mg tablets

15 mg = 3 of the 5mg tablets

12.5 mg = 2½ of the 5 mg tablets

- Some patients who are taking larger doses may also be prescribed the 50 mg tablets.

Examples: 75 mg = 1½ of the 50 mg tablets

60 mg = 1 of the 50 mg tablets plus 2 of the 5 mg tablets

Typically larger doses are prescribed initially, followed by a gradual dose reduction or 'taper'. Changes in dose are common so always check with your transplant team if you are unsure of your current dose

- **Never stop taking this drug suddenly**

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

MYFORTIC® (enteric coated mycophenolate sodium)

GENERIC NAME	BRAND NAME	REASON FOR USE
Enteric coated mycophenolate sodium Strengths: 180 mg and 360 mg tablets	MYFORTIC®	Myfortic® is an anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted tissue.

SIDE EFFECTS

1. DIARRHEA This side effect is common especially at higher doses. It can often be managed by taking smaller doses more frequently throughout the day. This should only be done on the advice of the transplant team.

2. STOMACH UPSET Nausea, vomiting, and abdominal pain can sometimes occur. These effects usually decrease with time. Report this to your transplant team if any of these become problematic.

3. DECREASED BLOOD CELL COUNTS Your blood cell counts will be monitored closely. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

4. INCREASED SUSCEPTIBILITY TO INFECTION Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

5. INCREASED RISK OF DEVELOPING CANCER The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

MYFORTIC® (enteric coated mycophenolate sodium)

TAKING YOUR MEDICATION

- Take this medication twice daily. Doses should be spaced 12 hours apart in order to maintain a consistent amount of drug in your body, *e.g.* 9:00 am and 9:00 pm. Always take your doses at the same times every day.
- Always be consistent with respect to Myfortic® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food). Tablets should not be cut, crushed or chewed.

INTERACTIONS WITH OTHER MEDICATIONS

Myfortic® may interact with other medications including:

Products containing iron such as ferrous gluconate, ferrous sulphate, ferrous fumarate or multivitamins plus minerals

Products containing magnesium such as Maalox® or Milk of Magnesia®

Cholestyramine (Questran®), a cholesterol-lowering agent

All of these medications can decrease the absorption of Myfortic® if taken at the same time. It is important that these medications be spaced at least 2 hours apart from Myfortic® (and at least 4 hours apart in the case of cholestyramine).

Please speak with your doctor, pharmacist or transplant coordinator before taking **any** new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors. Your pharmacist or transplant coordinator can help you plan your dosing schedule to avoid these interactions.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

COTRIMOXAZOLE (Septra®)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Sulfamethoxazole/ Trimethoprim or Cotrimoxazole Strengths: Single strength tablet (400/80 mg) Double strength tablet (800/160 mg)	SEPTRA® (and generics)	This drug is a combination of two antibiotics. It is used to prevent or treat a type of pneumonia called PCP. You are more susceptible to this infection when your immune system is suppressed.

SIDE EFFECTS

- 1. SKIN RASH** You may be allergic to the 'sulfa' part of the drug. If this occurs, stop taking this medication and report this to your transplant team. A different drug may be prescribed.
- 2. SENSITIVITY TO SUNLIGHT** Your skin may burn more easily if exposed to the sun. Avoid excessive exposure to sunlight and wear protective clothing or sunscreen products on all sun-exposed areas, even in the winter.
- 3. DECREASED BLOOD CELL COUNTS** Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.
- 4. FEVER** A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team *immediately*. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol®) may be used to control the fever.

HOW TO USE THIS DRUG

- This medication may be taken with or without food.
- Take this medication exactly as your doctor has prescribed. This may be once daily, or only on certain days of the week, or in some cases twice daily. Always follow the instructions given to you by your transplant team.

VALGANCICLOVIR (Valcyte®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Valganciclovir Strengths: 450 mg tablets 50 mg/mL oral solution	VALCYTE®	This medication is an anti-viral. It is used to prevent infections caused by viruses such as herpes virus and cytomegalovirus (CMV). It may also be used to treat infections caused by CMV.

SIDE EFFECTS

1. DECREASED BLOOD CELL COUNT Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.

2. GASTROINTESTINAL UPSET Diarrhea, nausea, vomiting, or stomach pain may occur. Taking the medication with food may prevent these side effects. If these symptoms are severe or last for more than one day, report this to your transplant team.

3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM This can include headaches or trouble sleeping. Report these symptoms to your transplant team if they become troublesome. Medications may be prescribed to help manage this.

HOW TO USE THIS DRUG

- If your doctor has prescribed a once daily dose of this medication it may be taken either in the morning OR the evening. Take the medication at the same time every day.
- If a twice daily dose of this medication has been prescribed, take it in the morning AND the evening, approximately 12 hours apart.
- Take this medication with food.

TAKING YOUR MEDICATION

- This medication is usually taken 3 to 5 times a day. Always follow the dosing instructions given to you by your transplant team.
- This medication may be taken without regard to meals, although taking it with food can help to prevent stomach upset.
- You may be instructed to increase your fluid intake while you are on this medication.

Appendix 2

Transplant Resource List

Toronto General Hospital Multi-Organ Transplant Program:
http://www.uhn.ca/Focus_of_Care/MOT/index.asp

DRUG COVERAGE:

Trillium Drug Program: 1-800-575-5386

<http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>

FINANCES:

Canada Pension Plan – Retirement Pension: 1-800-277-9914

<http://www.servicecanada.gc.ca/eng/isp/pub/factsheets/retire.shtml>

Canada Pension Plan – Disability Benefits: 1-800-277-9914

<http://www.servicecanada.gc.ca/eng/isp/cpp/disaben.shtml>

Employment Insurance – Sick Benefits: 1-800-206-7218

<http://www.servicecanada.gc.ca/eng/sc/ei/benefits/sickness.shtml>

Employment Insurance – Compassionate Care Benefits: 1-800-206-7218

<http://www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml>

Ontario Works:

<http://www.mcass.gov.on.ca/en/mcass/programs/social/ow/index.aspx>

Ontario Disability:

<http://www.mcass.gov.on.ca/en/mcass/programs/social/odsp/index.aspx>

- *Ontario Social Assistance Office Finder:* <http://appow.mcass.gov.on.ca/OfficeLocator/index.aspx>

CANADA REVENUE AGENCY: <http://www.cra-arc.gc.ca/>

Medical and Disability-Related Information:

<http://www.cra-arc.gc.ca/E/pub/tg/rc4064/rc4064-e.html>

Travel Expenses:

<http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbltrvl-eng.html>

Meal and Vehicle Rates Used to Calculate Expenses:

<http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns248-260/255/rts-eng.html>

Disability Tax Credit Certificate:

<http://www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html>

T.I.P.S – Tax Information Phone Service:

<http://www.cra-arc.gc.ca/esrvc-srvce/tps/menu-eng.html>

SUBSTITUTE DECISION MAKING:

Power of Attorney and Living Wills:

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.asp>

A Guide to Advanced Care Planning Booklet:

<http://www.culture.gov.on.ca/seniors/english/programs/advancedcare/docs/AdvancedCare.Guide.pdf>

LIVING DONOR:

http://www.uhn.ca/Focus_of_Care/MOT/Living_Donor/index.asp

ALCOHOL TREATMENT:

Drug and Alcohol Registry of Treatment (D.A.R.T): 1-800-565-8603

<http://www.dart.on.ca/>

SMOKING CESSATION:

Smokers' Helpline: 1-877-513-5333

www.smokershelpline.ca

Smoke-Free Ontario:

<http://www.mhp.gov.on.ca/en/smoke-free/default.asp>

Health Canada Health Concerns:

<http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/index-eng.php>

Appendix 3

Getting to University Health Network

Public Transit (TTC):

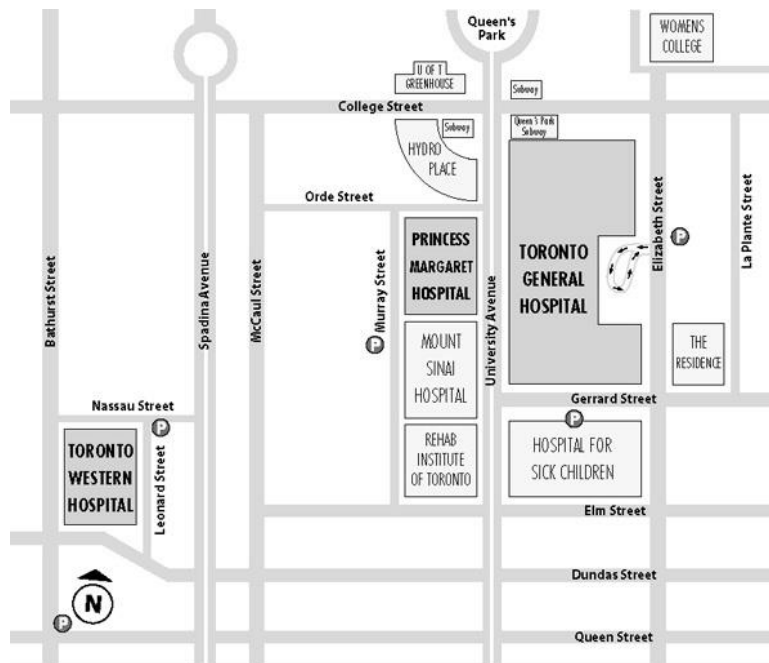
The Toronto General Hospital is well served by public transit. The Queen's Park subway station is located at the corner of College St. and University Ave. The College subway station at College St. and Yonge St. is only two blocks east of the Eaton Wing. Streetcars service College St. in both directions. Buses on Bay St. and University Ave. also have stops close to the Toronto General Hospital. For Toronto Transit (TTC) Information, please call: **416-393-INFO (4636)**

Parking: Patients and visitors can park in designated areas in the following UHN-owned parking lots:

- Gerrard Street: Patient/visitor parking only
- Elizabeth Street: First and second floors are reserved for patient/visitor parking
- Nassau St. lot: Patients/visitors only
- Fell Pavilion (Bathurst Entrance Underground Parking)

For current parking rates, please call the parking office at **416-595-7136**.

***Note: The Toronto Western Hospital is located at Bathurst St and Dundas St. Shuttle buses leave Toronto General Hospital from University Ave. entrance every 15 mins. This is a FREE shuttle and takes about 15 mins to get to Toronto Western Hospital.**



Appendix 4

Vaccines in Adult Transplant Recipients

Vaccine	Inactivated/ live attenuated (I/LA)	Recommended before transplant	Recommended after transplant	Monitor vaccine titers
Influenza	I	Yes	Yes *	No
	LA	No	No	No
Hepatitis B	I	Yes	Yes	Yes
Hepatitis A	I	Yes	Yes	Yes
Tetanus	I	Yes	Yes	No
Pertussis (Tdap)	I	Yes	Yes	No
Inactivated Polio vaccine	I	Yes	Yes	No
Pneumovax	I	Yes	Yes **	No
N. meningitidis (MCV4)	I	Yes	Yes	No
Rabies	I	Yes	Yes	No
Human papilloma virus (HPV)	I	Yes	Yes	No
Varicella (live- attenuated; Varivax)	LA	Yes	No	Yes
Varicella (live- attenuated; Zostavax)	LA	Yes	No	No
BCG	LA	Yes	No	No
Smallpox	LA	No	No	No

* In new patients we recommend that the flu shot be delayed until 3 months post-transplant to improve response

** Repeat dose every 5 years

Reference: Danzinger-Isakov L, Kumar D et al. Am J Transplant 2009;9(Suppl 4):S258-S262

Note : Reference Information courtesy of Dr. C. Rotstein MD FRCPC FACP, Co-Director Transplant Infectious Diseases, University Health Network

Important Contact Numbers

Contact	Telephone Number
Emergency	911
Toronto General Hospital - Main	(416)-340-4800
Toronto Western Hospital - Main	(416)-603-5800
Locating - Toronto General Hospital	(416)-340-3155
Pharmacy - Toronto General Hospital	(416) 340-4075
Transplant Physician:	(416) 340-4800 Ext:
Transplant Coordinator (Pre Transplant)	(416) 340-4800 Ext: 8072
Transplant Clinic	(416) 340-4800 x 4113
Ophthalmologist:	(416-603-5800 Ext:
Living Donor Program	(416)-340-4800 x 8072
Transplant Psych/Social Office	(416)-340-4800 x 5655
Patient Relations - University Health Network	(416) 340-4907
D.A.R.T	1-800-565-8603
Telehealth	1-866-797-0000
Registered Dietician - EatRight Ontario	1-877-510-5102
Life Labs	1-877-849-3637 or 416-675-3637