

# Transplant Digest

## National Living Donor Exchange Registry Launched

### Canadian Blood Services Partners with Canadian Kidney Transplant Programs

By Maureen Connelly, BScN, RN, C.Neph.C  
St. Michael's Hospital Living Donor Coordinator

The Canadian Blood Services has been given the task of building a national computer database for living donor paired exchange (LDPE). The database went live on January 29 2009 as part of a pilot program with St. Michael's as one of the pilot centres.



Living donor paired exchange provides a way for kidney donors who are incompatible with their intended recipient to still donate and help a person with chronic kidney disease receive a transplant. In exchange, their intended recipient receives a transplant from another kidney donor.

Donors may be incompatible with their recipient in two ways:

- 1) The donor's blood type is not the same as their intended recipient.\*
  - 2) The recipient has proteins in his/her blood called antibodies that react against donor blood cells.
- \* Blood group "O" donors can donate to any blood type.
  - \* Blood group "AB" kidney recipients can receive a living donor kidney from any blood type.

Living donor paired exchange is not new, in fact St. Michael's partnered with the University Health Network in 2004 to develop Canada's first paired exchange program. Similar programs are in existence in other countries.

The advantage of a national LDPE program is that the chance of finding a matching donor increases if there is a larger pool of potential



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A teaching hospital affiliated with the University of Toronto

pairs to select from. The electronic registry is a secure computer database that contains medical information about the incompatible donor-recipient pairs from across Canada. The database then compares information on all the pairs and identifies pairs that may be able to exchange donors.



If you wish to receive more information on paired exchange please contact:

Maureen Connelly RN BScN  
Living Donor Coordinator  
416-867-3676

or

Galo Meliton RN CNephC  
Transplant Recipient Coordinator  
416-867-3677

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### Disclaimer Note:

Views presented in this newsletter are those of the writers and do not necessarily reflect those of St. Michael's Hospital or the University of Toronto. Subject matter should not be construed as specific medical advice and may not be relevant to individual patient circumstances. For all questions related to your own health please contact your health care provider.

## From the Editor's Desk...

The Renal Transplant Program's primary focus is to provide the highest quality of patient care to kidney recipients and donors at every stage of the transplant process. A second focus is that as part of a large academic institution, we are also involved in teaching medical students, residents, fellows, and physicians from other hospitals, in order to spread our expertise as widely as possible both for the present and future. A third focus is clinical research, whose main purpose is to discover better ways of identifying health care concerns for recipients and donors, describing patterns within complex medical problems and their risk factors, and validating new transplant drugs as well as developing innovative ways to use existing medications.



In this issue of Transplant Digest there is a highlight of our preceptorship initiative and an article on transplant-related research. In our attempt to be “everything to everybody”, we also have information-packed articles on deceased donor allocation, the National Living Donor Exchange registry, common pretransplant questions, an encore presentation on that love-to-hate drug prednisone, and articles on gout and high cholesterol. Please feel free to contact the staff of Transplant Digest for further information on these or any past topics.

**Dr. Ramesh Prasad,**  
**Editor**  
Spring/Summer 2009

# Pre Renal Transplants Commonly Asked Questions

By Mari Vella, MSW and Meriam Jayoma-Austria, RN

## 1. How do I pay for my kidney transplant meds?

Paying for your medication is your responsibility. The transplant program does not provide funding for your medication. If you have private insurance, please check with the company about the specifics of the coverage. In addition, it is highly advised that patients apply for the Trillium Drug Benefit Program, a government assisted medication program.



## 2. My trillium deductible is too high, what can I do?

Trillium deductible is based on your previous year's household income based on your income taxes. Please talk to your dialysis social worker about your specific situation.

## 3. How often do I have to go to St. Michael's after my transplant?

The visit can vary depending on your condition after the transplant especially in the first three months. The clinic visit is very important for the monitoring of your transplant kidney.

## 4. How do I get to and from the transplant clinic after being discharged from the hospital?

Transportation is your responsibility. There is no transportation service provided by the transplant team. It is important that you have to plan ahead of time for going back and forth to the hospital for check up and blood work, after you are discharged, and you will probably have to draw upon personal resources like family and friends. If you have TTC's Wheel Trans, you may or may not be eligible for this service after the transplant.



## 5. How long do I have to wait for a kidney transplant?

The waiting time varies depending on your blood type. If your blood type is either "A", "B" or "O", the waiting time can vary from 7-10 years. If your blood type is "AB" it can range from 3-5 years. This means that people getting their kidneys *now* have waited this long. However, all of these can change depending on the availability of deceased donors.



## 6. Is there any funding for the time I'm off work?

You may be eligible for employment insurance benefits. For more information on your specific situation, you may ask the assistance of your dialysis social worker ahead of time.

## **7. Am I still qualified for disability insurance after my kidney transplant?**

Generally, if the sole reason of being on disability had been dialysis, then you are no longer eligible. Disability may be approvable by other physicians for non-transplant related conditions. For more details on your specific situation, please ask the assistance of your dialysis social worker.

## **8. What do I do if I am being called for a kidney?**

If you got the message in the voicemail that you are being called for transplant, return the call immediately. Please inform the caller if you are ill, or have been ill recently. Bring your medicines or copy of your medication list. You have to go to St. Michael's Hospital, 8<sup>th</sup> Cardinal Carter Wing right away.

## **9. I hate prednisone, is there a way to avoid taking this medication after the transplant?**

St. Michael's Hospital transplant program has a prednisone sparing protocol. However, your transplant nephrologist will decide whether you are eligible for this protocol or not.

## **10. What do I do if I have a live donor outside the country?**

The first step you have to do is to call the donor nurse coordinator, Maureen Connelly, at 416-867-3676 for information.

## **11. How soon can I go on the list after I had my pre-transplant assessment?**

It varies from patient to patient. The less complicated the medical condition of the patient, the faster they go on the list. Regardless of how long the work up takes, the list date will be based from the time he/she started dialysis.

## **12. If I am close to the top of the list, does St. Michael's provide a pager or cell phone?**



Contact phone numbers are very important. This is the only way that the transplant team can get hold of you if there is an available kidney for transplant. Unfortunately, St. Michael's transplant program doesn't provide a pager or cellphone. It is your responsibility to update your transplant team for any additional contact numbers and to be available 24/7.

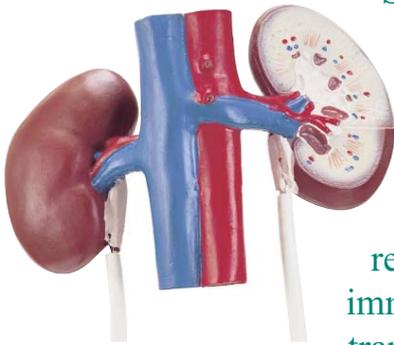
# How Kidneys from Deceased Donors Are Made Available In Ontario

## Information for those waiting for kidney transplants

Patients with kidney failure receive transplants according to a standard distribution method that is used by all transplant programs in Ontario. Fair and equitable access to deceased donor kidneys is the principle guiding the process.



In most cases, patients who have waited longest are selected for transplants first. But because organs available for transplant are so scarce, programs must also balance fair and equal access to transplants with achieving best health outcomes.



Several other factors are therefore weighed in the decision. Patients' medical conditions are an important consideration as some patients have medical conditions that require urgent transplantation. In addition to selecting those who can medically undergo the transplant procedure and who will have a long-term benefit from a donated kidney, the order of transplantation is influenced by the requirement to match donor organs with recipients based upon immunological criteria to prevent immediate rejection. Individual transplant centre wait lists also have an impact on wait time.

Kidneys for transplantation are therefore made available to patients in the following order:

- **Medical urgency.** These patients are likely to die without an immediate transplant
- Pediatric (under age 19) recipients
- Highly sensitized patients (patients who have developed immune responses from transfusions, pregnancies or previous transplants that make matching very difficult, like having a rare blood group)
- Very close genetic matching between donor and recipient that can enhance the length of time the transplant will work
- Matching of the donor and recipient age (to minimize wait time for older recipients and maximize the life of the donated kidney)
- Moderately sensitized patients (those patients with moderate immune responses)
- Time on the waiting list since starting dialysis

# Post-Transplant Chat

By Fernanda Shamy, RN, Jennie Huckle, RN, and Thelma Carino, RN

1

I have heard the word "gout" spoken a lot. What is it exactly?

Gout is an accumulation of uric acid (urate) crystals in the joints. These crystals are formed due to abnormally high levels of uric acid in the body. Uric acid is a waste product that results from normal body cell process and absorption of foods. It is present in the body naturally in small amounts. Human beings and primates are the only animals that cannot break down their uric acid, so it must be excreted by the kidneys and liver.

Gout is characterized by severe sudden pain, tenderness, stiffness, redness and swelling of joints. Gout is most often felt on the first joint of the big toe but it can also manifest itself in any other joint of the body. It usually occurs there because the toes are a little cooler than the rest of the body, allowing the crystals to come out of circulation there, and the toe joint is frequently traumatized during life activity, which also allows this to happen.

2

What are my risk factors for gout?

Common risk factors include genetics (family history), kidney disease, and elevated uric acid levels in the blood. Gout has been associated with obesity, diabetes, high blood pressure, and high cholesterol as well. Older men, but both men and women who are beer drinkers can get gout. Some medications such as diuretics (water pills) and anti-rejection drugs (cyclosporine) can lead to gout.

3

What sort of things can trigger a gout attack?

Surgery or a sudden severe illness, crash diets that are especially high in protein, and eating large quantities of high purine-rich foods like meat and meat products, wine, beer, and shellfish can precipitate a gout attack. Radiation therapy and a dosage change in your medications can also lead to a flare.



4

### What can I do to prevent or decrease gout attacks in the future?

First of all, it is important to treat your gout as soon as possible. Consult your health care provider for advice. Continue to take all your other medications unless told otherwise.



Maintain a healthy weight and exercise regularly. Do not take over-the-counter drugs or pills without the Transplant Office's knowledge since some of these can be very dangerous for your kidney. Avoid the foods that are listed in this feature, or if you are unable to do so or have concerns, spend some time with your dietician for specifically tailored advice.

5

### Is there anything in the diet that I can change to prevent future attacks?

Sweet breads, meat based broths, beers, meat and meat products, anchovies, spinach, lentils, asparagus, dried beans and peas, shrimps, sardines, oysters, scallops, clams, herring, lobster, yeast supplements and mackerel are some of the richest sources of purines. You must limit your intake of these.

6

### It is 3 a.m. and I have a gout flare. What should I do?

Rest the joint, and if possible cancel your activities for the following day since 24 hours of rest can be very helpful. Elevate the painful joint, apply cold packs to the joint several times during the day, and keep up with your fluid intake. Call your doctor or nurse in their office for further instructions, and continue to take all your prescribed medications on schedule in the meantime.



7

## Do I need medication for my gout? How is my response monitored?

Colchicine and allopurinol are often prescribed for gout, and sometimes the dosage of your prednisone (steroid medication) is increased. The use of these medications is complex and requires medical supervision, since if they are used incorrectly the gout may actually become worse, drug interactions or other serious side effects can happen, and the kidney transplant can become seriously damaged. Avoid over-the-counter non-steroidal agents (e.g. ibuprofen) if possible since they can injure the kidney. Be sure to tell your doctor that you have a kidney transplant before they prescribe any medication to you. Sometimes the dose or type of existing medication can be changed.

Your response is monitored clinically (i.e. absence of an acute flare) and by checking your blood uric acid levels periodically. Please bring up the topic of gout in your discussion during your transplant clinic visit if you have concerns. Sometimes you can also be referred to a gout specialist for additional advice.

8

## I have good pain tolerance so a little bit of arthritis doesn't seem like a big deal. Are there any other implications from having gout?

Some studies suggest that the risk for having a heart attack is increased in people who have gout, and the risk for progressive kidney damage is increased as well. Serious joint deformities can occur. Kidney stones can form. There are also the side effects from gout medication. Always tell your doctor or nurse if you have had gout so that something can possibly be done about it.



**The big toe is one of the common areas for gout attack**



# A Closer Look At Your Kidney Transplant Medications: Prednisone

Helen Fanous Pharm.D, Rph  
Pharmacist – SMH Renal Transplant Program

## What is Prednisone?

Prednisone belongs to a class of medications called corticosteroids (or “steroids” for short). It is commonly used in transplant patients to help suppress the immune system in order to prevent rejection of the transplanted organ. In fact, it was the first transplant medication ever to be used.

## What is the brand name for Prednisone?

This drug is available as generic only. In Canada, the manufacturer produces Prednisone as 1 mg, 5 mg and 50 mg tablets.



## How do I take this medication?

Prednisone is taken once a day in the morning. You may take this medication with food in order to prevent stomach upset.

## How much should I take?

Generally, the Prednisone dosage after transplantation will be high. During your transplant clinic appointments, your doctor will taper this dose over the few months following surgery. The rate of taper as well as your final dose depends on how your new kidney is function, amongst other factors.



Pills can be split or combined to arrive at your exact dose. It is important to take Prednisone exactly as prescribed by your transplant doctor. A cousin of prednisone called methylprednisolone can be given intravenously when you are having an acute rejection. The dose of

prednisone may also be increased after you have had an acute rejection, or if the dose of one of your other transplant medications needs to be decreased for another reason.

## What are the potential side effects that may occur?

The most common side effects are listed below:

- Increased Blood Sugar: Screening for elevated blood sugar after transplant can help detect this. Sometimes oral drugs or insulin is needed to help control blood sugar levels while on Prednisone. Your doctor will gradually decrease immunosuppressive medications over time and this can help improve blood sugar levels. Dietary modification can be very useful.
- High Blood Pressure: In addition to salt restriction, there are several medications that may be used to help control blood pressure after transplantation.
- High Cholesterol: Diet and medications may be used to help control high cholesterol.
- Weight Gain: Prednisone can cause an increase in appetite resulting in increased body fat, and also cause you to retain water causing swelling or “edema”. It also may cause a puffy or “moon-face” appearance.



- **Mood Changes/Insomnia:** Occasionally, some patients experience mood swings with this medication. Many patients also find it difficult to sleep when taking high doses of steroids. This is why it is important to take Prednisone in the morning and not close to bedtime. Be sure to let the transplant team know if you are taking any medication for depression or other psychiatric problems.



- **Bone Thinning (Osteoporosis):** Prednisone may accelerate the process of bone loss. The transplant team will check to see if Prednisone is affecting your bones by scheduling a bone mineral density test after your surgery.
- **Others:** There may be an increased susceptibility to infections, cancer, joint erosion (“avascular necrosis”), stomach acidity, cataracts, and heart disease.

### **If prednisone is so bad, can it be stopped or avoided?**

Prednisone is the longest surviving transplant drug around because it is so useful. Many transplant doctors think that it is indispensable and required to ensure a long and healthy transplant life. However, research is ongoing to look for ways of avoiding, withdrawing, or at least minimizing, the use of steroids after kidney transplantation. In select situations the transplant team may choose to try to avoid prednisone altogether. If you would like to avoid prednisone, please have a discussion with your doctor before and after the transplant to understand the risks and benefits of this approach.

### **Are there any drug interactions associated with Prednisone?**

Prednisone can interact with many medications. Always discuss with the transplant team before starting any new medications - either prescribed or over-the-counter.



# High Cholesterol and Transplantation

By Dr. Ramesh Prasad

It is quite common for kidney transplant patients (about 70%) to have a high blood cholesterol level. This is important to know for many reasons. High cholesterol is a major risk factor for heart attacks in the general population, and there is no reason to believe that this is not true for transplant recipients as well. Patients with kidney disease may also have a form of cholesterol (oxidized LDL) that can more easily lead to plaques and blocked blood vessels. In the future more transplant patients are in fact likely to die from heart disease than from kidney failure. A high cholesterol level may also indirectly affect the function of your kidney transplant by causing or making acute rejection or chronic rejection worse.



The Transplant Clinic screens patients with a fasting lipid profile (that includes the total cholesterol, HDL or “good” cholesterol, LDL or “bad” cholesterol, and triglycerides) at least once every six months. Please ensure that you have fasted for at least 8 hours (preferably 12) prior to the blood draw. It is your responsibility to ensure that your cholesterol record in the clinic is up-to-date. That way you can be informed about your level when you come to the clinic, or be called by telephone if it is very high. Laboratory results are robust, so unless the initial test was non-fasting, a repeat test for confirmation is not required.

There are several reasons why cholesterol levels can be high. A genetic predisposition, the remnant effects of your original kidney disease, protein loss in the urine, transplant drugs (cyclosporine and tacrolimus, prednisone, and sirolimus), and the effects of aging can all play a role. Diet, however, is one risk factor that can be modified. Control of your total caloric intake will have the biggest impact. Obese patients must lose weight.



Saturated fat must be kept low, and no more than 30% of your total calories should come from fat. High triglycerides can be controlled by reducing your sugar and alcohol intake. The HDL can be improved through exercise. Often, however, a multi-pronged approach is necessary and ongoing consultation with a dietician is required to arrive at a patient-centered, often culture-specific dietary prescription.

Sometimes non-transplant drugs can promote a high cholesterol level. Examples include thiazides and beta-blockers, which are drugs used for hypertension. Your doctor may wish to change the type or dose of either your transplant anti-rejection drugs or other drugs to help control your cholesterol level. Of course, this will be helpful only if you adhere to your prescribed diet and exercise regularly.

It may be necessary to start a specific cholesterol-lowering drug to bring your blood cholesterol level down to target. HMG-CoA reductase inhibitors (also known as “statins”) are powerful drugs that can lower cholesterol levels effectively. Examples of drugs in this class include

simvastatin, fluvastatin, pravastatin, and atorvastatin. Discuss with your doctor the relative merits of these drugs and to help decide which one is right for you. Other classes of drugs include the fibrates (e.g. fenofibrate), typically prescribed when the triglycerides are high, and ezetimibe, a cholesterol absorption inhibitor. Niacin and fish oil are other, less popular options for cholesterol control. Finally, it is imperative that you avoid herbal or natural health products to try to lower your cholesterol. These products contain unregulated amounts of statin-like substances that can seriously injure your muscles or liver, and interact with your transplant drugs, endangering your kidney as well.



When cholesterol-lowering drugs are prescribed, blood monitoring for muscle and liver enzymes is often performed to ensure that you are tolerating them well. A follow-up fasting cholesterol may also be ordered sooner than scheduled. There is some evidence that statins can in fact improve other aspects of your health besides the cholesterol, such as blood pressure and bone mineral density.

Deciding on the “target” cholesterol level with treatment is decided often on a case-by-case basis. This usually depends on your current level of risk for having a heart attack. For most patients, a total cholesterol level of less than 5.2 is ideal. The HDL cholesterol should be more than 1.0 for men and 1.2 for women, the LDL less than 2.5, and triglycerides less than 1.7 (all numbers in mmol/L). Please discuss with your doctor your particular cholesterol and triglyceride targets. The Transplant Program has also done several research projects involving high cholesterol and its therapy. Ask the Transplant Team about these at your next visit if you are interested in learning more.

# Preceptorship is alive and well at the St. Michael's Hospital Renal Transplant Program

Galo Meliton, RN, C Neph (C)

The St. Michaels Hospital Renal Transplant Program had the privilege and opportunity to do a full day Preceptorship for the Renal Transplant Team from Notre Dame Hospital in Montreal, Quebec on November 12, 2008.

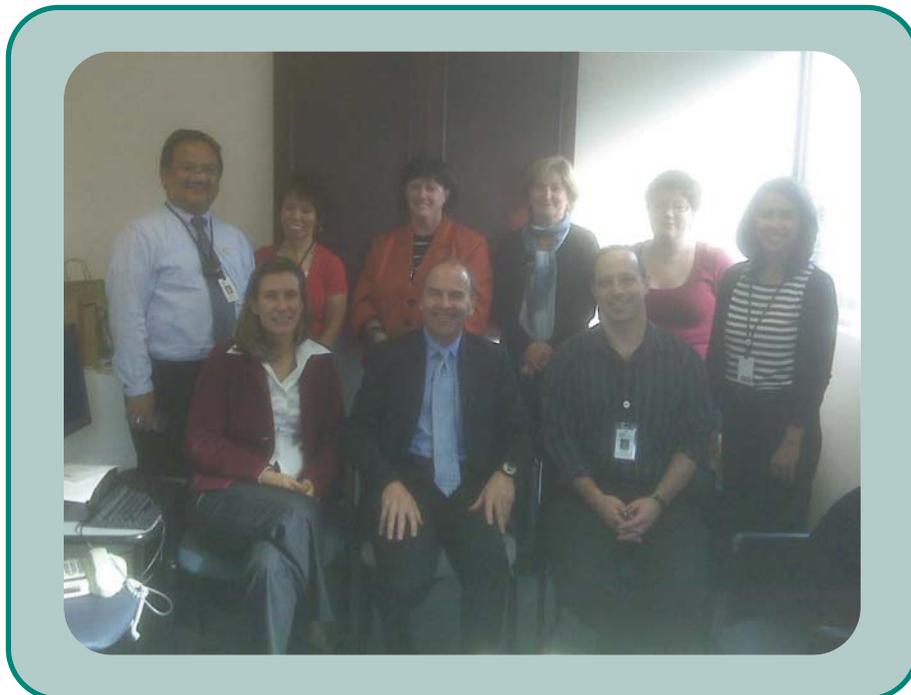
The purpose of this event was to share our expertise in different aspects of the Living Donor Program with our visitors with the hope that they will go home with ideas to make recommendations to their own team in order to increase their transplant numbers.

The event was kindly sponsored by Astellas Pharma Canada, Inc., represented by Oleg Boldireff and Josee Boulianne.

Headed by Dr. Michel Paquet, Transplant Nephrologist, the rest of the team from Notre Dame consisted of Dr. Mona Beaunoyer, Transplant Surgeon, Julie Guertin, Living Donor Transplant Nurse, and Jo-Ann Fugere, Living Donor Medical Technologist.

A big thank you goes to Trixie Williams, Clinical Leader Manager in the Ambulatory Clinics for her support toward this event and all who participated in the Preceptorship: Dr. Jeffrey Zaltzman, Medical Director of the Renal Transplant Program, Dr. Jordan Weinstein, Donor Nephrologist, Jill Campbell, DCCP Program Director, Dr. John Honey, Staff Surgeon, Dr. Dae-Gyun Chung, Staff Radiologist, Maureen Connelly, Living Donor Coordinator, and Sharon Lee, Social Worker. The recipient and post transplant teams spent some time with our visitors as well.

The event was mutually gratifying for all parties involved: "It was a wonderful feeling having been part of this process; it was such a pleasure knowing that we were able to share our experience with them", said Dr. Zaltzman.



**L-R (Front):** Dr. Mona Beaunoyer, Dr. Michel Paquet, Dr. Jeff Zaltzman

**L-R (Back):** Galo Meliton, Jenny Huckle, Maureen Connelly, Jo-Ann Fugere, Julie Guertin, Meriam Jayoma-Austria

# TRANSPLANT RESEARCH

## Thank You! – Thank You! – Thank You!

The Kidney Transplant Research Team at St. Michael's Hospital would like to sincerely thank all of our kidney transplant recipients, kidney donors and healthy volunteers who have participated in research studies in the past and who are involved in research studies now! Hundreds of patients have participated over the years and we really appreciate all the time and effort that you have contributed!

Many of the drugs, devices and technologies that are now used for providing transplant patient care at St. Michael's Hospital were at one time tested for their safety and efficacy on volunteers in research studies.

The St. Michael's Hospital Kidney Transplant Research Team members currently are:

|                      |                                     |
|----------------------|-------------------------------------|
| Dr. Jeffrey Zaltzman | Study Investigator                  |
| Dr. Ramesh Prasad    | Study Investigator                  |
| Michelle Nash        | Research Manager                    |
| Lindita Rapi         | Research Coordinator                |
| Sulagna Sarker       | Research Coordinator                |
| Weiqiu Yuan          | Research Assistant                  |
| Michael Huang        | Research Assistant and Statistician |

The Kidney Transplant Research Program at St. Michael's Hospital is actively involved in a number of research studies for both kidney transplant recipients and donors.

Most of the funding for our research studies comes from sources outside of the hospital including the pharmaceutical industry, granting agencies such as the Kidney Foundation of Canada, the Canadian Institute for Health Research (CIHR), the Heart and Stroke Foundation of Ontario (HSFO), academic institutions such as the University of Toronto and private donations.

We are involved in both Investigator-initiated research with studies that have been written by Dr. Zaltzman and Dr. Prasad as well as multi-centre national and international studies that are sponsored by granting agencies or the pharmaceutical industry.

We conduct both clinical drug studies and observational research that can involve single visit, short or long term

follow-up, database chart reviews, patient questionnaires and various tests and procedures.

If you should have any questions about a specific study or any questions about research in general, please do not hesitate to contact Michelle Nash, Transplant Research Manager at (416) 867-3692.

### Q: Do I have to participate in a research study?

A: Research is always voluntary. If you decide not to participate in research, you will continue to receive the highest quality of care at St. Michael's Hospital. You will not be penalized in any way. You can stop participating at any time during a study. It is important that you understand what is involved in a research study before agreeing (also called consenting) to participate. Feel free to discuss the study with family members, your family doctor or anyone else.

### Q: Once I'm approached about a research study, what will I be asked to do?

A: If you are approached to participate in a research study, you will be asked to read a Letter of Information and Consent Form that will provide you with more information about the research study. You may also be asked a series of questions to make sure that you are eligible for the study.

### Q: Does anyone at the hospital review research studies before they begin?

A: The Research Ethics Board at St. Michael's Hospital is a group of scientific and non-scientific people who review research involving human participants by following regulatory guidelines. This group is also required to do periodic review of ongoing research studies.

### Q: How will my privacy be protected?

A: All researchers are required to prepare a plan for how they will protect patient information that is reviewed for research purposes. The privacy plan is approved by the Research Ethics Board prior to the research commencing. No participants are ever identified in the results of any transplant research studies.



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