March 10, 2011 is World Kidney Day (WKD). WKD is a joint initiative of the International Society of Nephrology (ISN) and the International Federation of Kidney Foundations (IFKF). Its main objective is to raise awareness on the importance of kidney function in overall health. More than 5% of the adult population have some form of kidney impairment, and millions die each year from heart diseases linked to Chronic Kidney Disease (CKD) (www.worldkidneyday.org). This year's theme focused on the link between CKD and cardiovascular disease, hence the slogan: Protect Your Kidneys and Save Your Heart.

St. Michael's Renal Transplant program joined our global partners in raising kidney health awareness by conducting an interactive health information session for the hospital community. The event was made possible with the sponsorship of Astellas Pharmaceuticals, SMH Risk Modification Department through Dr. Vuksan’s team, the support of the managers within the Diabetes Comprehensive Care Program (Trixie Williams, Colleen Johns, and Pam Robinson), and all the staff in the Renal Program who helped during the information session.
From the Editor’s Desk

Regular readers of Transplant Digest know that the primary purpose of the publication is to disseminate information to patients, their care givers, and interested non-transplant health care providers. Topics are selected to be complementary but not overlapping, and to cover most of the important areas of transplant medicine over several issues. Based on the feedback received it appears that this objective has been accomplished. The editors thank all the present and past contributors to Transplant Digest in helping to make it a success.

Another important objective of Transplant Digest, however, is to disseminate announcements in addition to the notifications sent out via the notice board or mailed leaflets. If they seem repetitive, it is only to emphasize their importance.

Our Registered Nurses take centre stage in this issue with their articles on foot care, travel, exercise, and the pre-transplant process. Please read these very practical, reader-friendly reviews. Our medical content consists of reviews about post-transplant hyperparathyroidism and commercial transplantation.

We continue to actively participate in World Kidney Day in March. We have an article on the experience of transplantation written by one of our transplant recipients, complementing a contribution from a previous issue by one of our donors.

Dr. Ramesh Prasad
Editor

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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.

Welcome!

IMELDA LO, RN
She will be working as a part time RN within the Renal Program.
Commercial Kidney Transplantation: Why it is Wrong!

Dr. Ramesh Prasad

Patients legally resident in Ontario are entitled to receive a living donor or deceased donor kidney transplant provided they are medically suitable and eligible, with very few exceptions. Particularly in the case of a deceased donor transplant, however, this will involve a waiting time of several years due to the great demand for these organs and the presence of a waiting list, classified by blood type. Eventually, however, as long as patients stay reasonably healthy while on the list, they will get a transplant. By far waiting time, determined by the dialysis start date, is the main factor in deciding which patient ultimately receives a particular kidney when it becomes available.

Unfortunately, some patients are not willing to abide by these rules. They try to circumvent this waiting time by going abroad, getting a kidney, and then coming to the Transplant Clinic to receive ongoing care. Although in some cases this is because the donor, a close relative, is unwilling or unable to come to Canada for donation, in which case it is perfectly legal, more often it is because the patient with kidney failure wishes to purchase a kidney from a vendor. This practice is illegal in Canada and most parts of the world. It is strongly condemned by the Declaration of Istanbul 2008 (www.declarationofistanbul.org), a document which has been endorsed by more than 100 organizations including the Canadian Society of Nephrology, Canadian Society of Transplantation, and the Kidney Foundation of Canada.

What is so wrong about paying someone for their kidney? The problems are both medical and ethical. Let us discuss the medical problems first. The Transplant Clinic has seen numerous complications from such surgeries that have been performed in unhygienic conditions. Patients suffer urine leaks, and have presented with severe infections, sometimes fatal. Such infections are not commonly seen in Canada and are resistant to most antibiotics. The kidney transplant itself is often lost. The outcomes from these transplants are worse than the local, legal transplant results seen in the countries where these transplants are performed, because they are being performed illicitly. When these patients arrive, hospital documentation is poor or even absent. This makes caring for patients very difficult. How about the donor? One study showed that these donors are typically very poor, and despite selling one of their kidneys, they are unable to clear their debts.

They also suffer medical problems afterwards, with no one to care for them. In fact, they receive only a small percentage of money paid by the recipient. Most of the money actually goes to brokers and other middlemen. It turns out that most donors do not recommend to others that they sell their kidneys.

What are the ethical issues? It seems very wrong to exploit the poorest and most vulnerable sections of society, who are driven to sell their organs out of desperation driven by their poverty. Most experts believe that a regulated system of payment cannot solve this issue, because there will always be exploitation of the poor by the rich. Although legal donation is almost perfectly safe for the donor because they have been properly screened, there is no study to date which has shown that it is safe for the commercial donor. No one would take a drug that has not been properly tested, so why would one take an organ from a donor when it has never been shown to be safe for the donor?

Brochures in many languages are available for download from the Declaration of Istanbul website explaining the reasons why commercial transplantation is wrong. The Transplant Clinic shares information regarding this practice to transplant candidates considering getting a commercial transplant, if they are open enough to tell us about their plans ahead of time. The Transplant Clinic does not ever communicate with foreign centres performing these transplants.

All hope is not lost for patients facing many years on the waiting list. Numerous initiatives have been put in place by various organizations to increase living donation and deceased donation rates, such as desensitization, paired exchange, a national exchange registry, improved consent processes for organ retrieval, etc... These are really making a difference. The waiting list and waiting times are getting shorter. Our post-transplant outcomes are among the best in the world. Getting a kidney in Canada is indeed the best option for transplant candidates!
MARK YOUR CALENDAR!!!
St. Michael Renal Transplant Program Presents……
Forging Ahead with Excellence in Patient Care
MAY 25, 2012
at the Li Ka Shing Knowledge Institute (St. Michael’s Research Building), located at Victoria and Shutter Street

MORE DETAILS TO FOLLOW......
Pre-Transplant Clinic Implements Change in Process
Galo Meliton, RN, C Neph (C)

This Article is adapted from the Poster entitled Improving Patient Flow, Access, and Wait Time to Transplant which was created and presented by J. Chen, RN, BScN, MN, CDE, CPT; M. Connelly, RN, BScN, M. Jayoma-Austria, RN, C Neph(C); G. Meliton, RN, C Neph(C); M. Rivers, RN, BScN, CDE at the recent DCCP Research and Education Day.

Every aspect of the Renal Transplant Program at St. Michael’s Hospital including the Pre-Transplant Clinic strives hard to ensure that our processes meet our patients’ and their family’s needs. The pre-transplant program provides assessments for patients considering kidney transplantation. The tremendous growth experienced by the program over the past 10 years coupled with our commitment to continuous quality improvement prompted an internal review of our pre-transplant process. On August 6, 2010 we had our Transplant Program Transition Day where we collaborated as a team to identify our strengths and areas for improvement to accomplish our mission.

Through this review process, we identified that completion of the initial pre-transplant assessments by the Nephrologists was delayed due to incomplete referral packages, and live donors were sometimes evaluated before their intended recipient had been assessed for transplant suitability. A major flaw in the old system was that we took ownership for a lot of the testing for the recipients with potential living donors. The new process vision was to implement an efficient and transparent standardized process in managing pre-transplant referrals. The goal now is to have the potential recipient’s workup completed by the referring center, received and reviewed by the recipient team prior to the potential recipient being seen by the Transplant Nephrologist; and as long as there were no “red flags” identified in the potential recipient’s preliminary chart review, a live donor work up could then be initiated.

The goals of this project include:

1. To decrease time for an initial appointment with a Transplant Nephrologist for pre-transplant assessment in the living donor program to less than 3 months.
2. To decrease wait time for an initial appointment with a Transplant Nephrologist for pre-transplant assessment in the deceased donor program to less than 6 months.
3. To decrease the time from the date the referral is received to the date the patient is transplanted to less than 6 months for direct live donor transplants.
4. To decrease the time from the date the referral is received to the date the patient is added to the deceased donor wait list to less than 1 year for deceased donor transplant candidates.

An important part to this change in process was ensuring that the internal staff education as well that of our external partners, our referring centers’ staff is performed. Several steps also had to be taken before information was disseminated to our referring centers. The existing process was mapped out and analyzed, opportunities were identified to improve the process, and policies and new documentation relevant to the new process were developed. The pre-renal transplant database was enhanced in order to reflect and track wait times electronically.

Early in September 2010, we invited representatives from all our referring centers to provide them with the necessary information and tools to implement this new process, effective September 30, 2010. There was tremendous support and the new process is still very well received. The next step was to have a project review 6 months later to determine any need for revisions of the process. If we stick with this new process, ongoing education will be provided to the transplant staff and our referring centers as needed.

Two distinct effects have been seen since this new process was implemented: recipient testing is now arranged by the referring center and completed prior to the potential recipient being referred to the pre-transplant program, and the live donor and recipient work ups are coordinated with clearly defined communication points and documentation tools.

The authors of this project would like to acknowledge the help from Susie Par (Clerical Assistant), Mari Vella (Social Work) and Niki Dacouris (Database Coordinator).
Transplant patients as well as those with diabetes are at risk for foot problems such as fungal infections and foot ulcers. Other risk factors for foot problems include smoking, nerve damage, poor circulation and being overweight. Feet are prone to great strain due to hours of constant movement and pressure. General common sense and good foot care habits may help prevent foot problems.

**Tips to Keep your Feet Healthy**

1. **Keep your feet clean and dry**
   - Feet should be washed at least once a day. If your feet sweat a lot you may need to wash them more often. Dry your feet with a fresh towel and be sure to dry well between each toe to help prevent fungal infections or athlete's foot. A non-scented lotion may be applied to the foot, but avoid using in-between the toes. If you have psoriasis, eczema or tendency to develop athlete's foot it is important to avoid use of scented lotions due to possible irritation.

2. **Wear fresh clean cotton socks and well-fitting shoes**
   - Cotton socks allow feet to breathe better than synthetic fibers.
   - Whenever possible wear white socks-if you have a cut or sore, the drainage will be easy to see.
   - Do not wear other people's shoes as fungal infections can easily spread this way.

3. **Cut your toe nails properly**
   - Cut nails straight across with clippers or scissors. Edges should not be cut round the corners as this may cause ingrown toenails. If there are sharp edges, these can be buffed or filed. If you are unable to do this yourself seek professional assistance. While having a pedicure, wearing toenail polish etc... is acceptable, make sure that the place you go to for these services is clean and sanitary.

4. **Check your feet for problems**
   - While washing your feet, look for cracks, blisters, warts, ingrown toe nails, corns, scratches or cuts.

   • Use a hand mirror to see the bottom of your feet or ask someone else to check them for you.
   • Look for discoloration of the nails. This may be a sign of a fungal infection.

5. **Protect your feet**
   - Don't walk barefoot, even indoors
   - Wear shower shoes at the gym, in locker rooms and public pools to prevent fungal infections.
   - Don't put hot water bottles or heating pads on your feet, especially if you have numbness.

6. **Keep a healthy lifestyle**
   - Exercise regularly
   - Maintain a healthy weight
   - Avoid smoking

**When to see your Doctor**

See your doctor if you have any swelling, warmth, redness or pain in your legs or feet.

Don't attempt to self-treat any foot problems such as corns, calluses, in-grown toenails, slivers or warts. You may do more harm than good. Your doctor may treat your foot problem or refer you to a foot specialist.

**Toe nail Fungal Infection**

Toe nail fungus or Onychomycosis is a very common condition that can destroy or disfigure the nail. The little toe or the big toe nails are most commonly affected. This type of fungi grows well in warm, moist environment such as the shoes. Once the fungus grows, it spreads to the feet and feed on the (Keratin) which is the protein that nails are made of. The affected nail will become yellow or brown and thick. The nail may become very thick making wearing shoes painful. Foul smelling debris may develop under the nail and in some cases eventually the nail may crumble and fall off. Your doctor may prescribe a topical or oral medication to treat your toe nail fungus infection.

**Tips to keep in mind if you go to the foot spa**

Microorganisms that may be present in spas will easily enter broken skin and cause infection. It is therefore important that you:

• Do not shave your legs, use hair removal creams or wax during the 24hrs before going to the spa.
• Do not go to the spa if you have open sores, bruises, scratches, cuts, poison ivy or bug bites.

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General foot care
Fernanda Shamy, RN and Tess Montada-Atin, RN
Travel-Post Transplant
Thelma Carino, RN

Now that you have a new transplant kidney, your plans to conquer the world are endless. In this segment we will address some of the most commonly asked questions about travel in general. Please discuss your travel plans with the Transplant Clinic before making firm, and sometimes expensive, arrangements.

1) When can I travel after my kidney transplant?
If traveling within Canada, you may make plans to travel 3 months after your transplant. This may of course be delayed if there are complications after the transplant. If traveling outside Canada, you will be required to wait for a year. After this time the highest risk for most complications including rejection has largely passed. Again, this cannot be a firm promise. At all times you must ensure that it is relatively simple to get back to Canada, and that you have some assurance of access to a kidney or transplant specialist in the countries in which you are traveling.

2) The country that I plan to visit requires vaccination or immunization. Is it safe for me to get these vaccines?
Vaccines that are synthetically manufactured and vaccines derived from dead virus are generally safe to receive. Your response to these vaccines, however, may be variable. On the other hand, vaccines obtained from a live organism (e.g. live attenuated virus) are not recommended for post transplant patients.

3) Where do I go to find out if I need vaccination to visit a particular country?
Travel Clinics will be able to assist you on the kind of vaccines you need to get. There are numerous such locations within Toronto and its surrounding areas. There is also a website called Travelers Health Website and you can log on to http://www.cdc.gov/travel/destinat.htm. This website will inform you of current diseases and illness occurring in a particular region, what vaccination is required, specific health risks and precautions to take to stay healthy during your vacation. However, we advise you speak to a physician specializing in Travel Medicine. The Transplant Clinic does not provide travel-specific advice.

4) Can I get vaccines from my Family Physician?
You may ask your Family Physician if they provide this service.

5) I was informed that I should bring a travel letter. Where do I get it?
A travel letter contains the critical information that you are a transplant recipient. It will include your lists of medications, and some relevant recent bloodwork. It also includes our office telephone and fax numbers and the name of a Transplant Nephrologist. This is helpful information in case you need to go to a hospital or emergency room, and helps with taking your medication across borders. Requests for a travel letter may be made at the time of your clinic visit or you should call transplant office at least 2 weeks in advance.

6) I am traveling to a country in a different time zone. Who do I call to help me on how to adjust medication times?
Talk to your Pharmacist about how to adjust your medication schedule. Generally, you should stick to the local timings when taking all your medications.

7) What precautions should I take while on vacation?
Remember that you are not the same as everybody else on vacation. Although you are on vacation the care of your transplant kidney is ongoing. Before you leave, know where is the nearest hospital and /or transplant center in case of an emergency.

Avoid dehydration especially if going to a warm country. Drink plenty of water. You may want to drink bottled water especially in areas where water sanitation is a concern. Drinking boiled water is even better.

Avoid swimming in stagnant waters. You might get bacteria or parasites that might make you very sick. Wear proper footwear in wet areas since some parasites enter your body through the skin of your feet. If you choose to go to a spa, make sure that the highest standards of cleanliness are in place.

Avoid sun exposure when sun rays are the strongest between 10:00 am - 4:00 pm. Always use proper sunscreen (SPF30 or higher). Apply this to all exposed areas of your skin. Wear sunglasses, a broad rimmed hat and protective clothing.

Avoid areas that are mosquito infested. Use insect repellant with DEET to protect your skin.

Take enough medication with you plus some extra doses just in case your stay is extended. Remember, the transplant clinic cannot call in prescriptions to pharmacies outside Ontario at any time due to licensing issues. If you are prescribed medications by a local professional feel free to call the Transplant Clinic. If possible, know the generic name of your medication since trade names for common medications may be quite different in other countries and unrecognizable to us.

Bon Voyage!
Post Transplant Exercise
Jennie Huckle, RN

Exercise is any type of physical exertion one performs in an effort to improve health, shape one's body, boost performances and self esteem.

Exercise will become an important part of the daily routine once you are discharged from the hospital.

Regular exercise has many benefits:

a) Improves circulation.
b) Build energy levels so you can do more activities without becoming tired.
c) Strengthens your heart and improves circulation.
d) Increases endurance.
e) Lowers blood pressure
f) Improves muscle tone and strength, thereby improving balance and joint flexibility.
g) Strengthens bones.
h) Helps reduce stress, tension, anxiety and depression.
i) Improves sleep.
j) Makes you feel more relaxed and rested.

It is best to start your exercise routine gradually by walking and increase the speed, distance and intensity as your health improves.

Also at this time you can choose the type of exercise you enjoy.

If possible try to recruit a family member or a friend to exercise with.

Exercise does not have to be costly.
The local Mall is a good place to start especially in the cold weather.

To tone up the upper body, one can use can goods as weights.
The Community Centre is another avenue to participate in some appropriate exercises such as swimming, walking on the Treadmill or biking on the Stationary Bike.

Avoid buying expensive gym membership until you are ready and certain you will use your membership regularly.

EXERCISE PRECAUTIONS:

Avoid heavy lifting, pushing heavy objects and contact sports in the early stages of post transplant when your wound has not yet fully healed.

Avoid exercising outdoors when it is too cold, hot or humid. Extreme temperatures can interfere with breathing difficulty and chest pain:

1) Stop exercising and rest if you experience pressure or chest pain.
2) Feel weak and dizzy or lightheaded.
3) Have unexplained weight gain or swelling (call your doctor).

Plan to exercise in the morning when you have more energy.

Wait at least 1.5 hours after eating a meal before exercising.

Dress for the weather condition and wear appropriate and protective footwear.

Take time to warm up approximately 5 minutes, stretching and marching on the spot prior to starting and the best cool down is to slowly decrease the intensity of the exercise and then do the stretching as in the warm phase.

Enjoy and commit for the moment with a long term gain.

If you have any doubts at any stage, please ask about exercise at your Transplant Clinic visit.
We are here to help!
Persistent hyperparathyroidism and hypercalcemia following kidney transplantation

Dr. Jeffrey Zaltzman

The Problem

Following a kidney transplant, some patients may have elevated blood calcium levels (hypercalcemia). This is a direct result of problems that have been carried over from dialysis. The development of hypercalcemia correlates with the duration of dialysis and parathyroid gland size and appears to be secondary to hyperplasia (growth) of the parathyroid glands. These are 4 glands that are found adjacent to the thyroid gland in the neck. As a result of kidney failure, the calcium/phosphate axis gets perturbed. With renal failure the kidneys lose their ability to excrete the dietary load of phosphate contained in many foods. At the same time, the calcium levels fall because the failing kidneys cannot make active Vitamin D (1,25 dihydroxy Vit D) which is involved in calcium absorption in the gut. As a result, the body responds by increasing parathyroid hormone (PTH) from the parathyroid glands. The elevated PTH acts on many tissues, but primarily on the bone, which then undergoes high turnover releasing calcium back into the blood. While on dialysis, patients try to control this problem with medications which bind the dietary phosphate, and taking Vitamin D supplementation. However despite these interventions, the parathyroid glands can become enlarged (hyperplasia) and become overactive. Persistent hyperparathyroidism (HPT) can be observed after renal transplantation. Some have reported that the incidence is approximately 30 to 50 percent. The degree of parathyroid hyperplasia can be so great in this setting that, although the parathyroid glands involute after transplantation, this process takes a few months (if mild) to several years or to reach completion. On occasion this never happens.

Following a successful kidney transplant in addition to hyperparathyroidism, other factors can also contribute to an elevation in the plasma calcium concentration:

- Resorption of soft tissue calcium phosphate deposits, which is often associated with persistent hyperphosphatemia
- Normalization of Vitamin D production, which both increases the PTH effect on bone and directly enhances intestinal calcium absorption
- Enhanced tubular calcium reabsorption by the new kidney transplant

In those patients who develop hypercalcemia, the plasma calcium concentration frequently begins to rise in the first 10 days after transplantation; however, this response can be delayed for six months or more. In some cases, acute severe hypercalcemia (plasma calcium concentration above 3.1 mmol/L) occurs soon after transplantation, and can cause acute kidney allograft dysfunction and confusion (mental status change).

Clinical and Biochemical features

- High plasma calcium (>2.60 mmol/l)
- High levels of PTH (30 pmol/l)
- Kidney transplant dysfunction (rising creatinine)
- Bone pain (PTH acting on bone), with bone disease
- Neurologic symptoms (confusion, fatigue)
- Vascular calcification
- Loss of fluid volume

Treatment

For all these reasons, effective control of persistent HPT is an important therapeutic goal after renal transplantation.

Acute therapy:

If the calcium is very high, treatment may need to be initiated urgently. Acute treatment includes expansion of blood volume with intravenous normal saline. Furosemide (Lasix) may be given, but volume with intravenous normal saline. Sometimes patients require surgical removal of the hypertrophied parathyroid glands (parathyroidectomy). There are two major indications for parathyroidectomy in renal transplant patients: severe symptomatic hypercalcemia, usually occurring in the early post-transplant period, and persistent, marked hypercalcemia.

Chronic therapy:

If the calcium level is only slightly elevated, there is often no specific treatment given, except to follow the calcium with routine blood tests. Treatment is considered in more severe cases. As hypercalcemia limits the use of vitamin D analogs, the use of cinacalcet (Sensipar®) a calcimimetic drug, is being increasingly studied. Studies have found that serum calcium concentration normalizes with cinacalcet therapy. The effect of cinacalcet on PTH and serum phosphorus varies across studies. Cinacalcet is NOT currently approved for this indication among transplant patients. Further study, particularly of safety issues, is required to clarify the role, if any, for cinacalcet. We are currently enrolling transplant patients at St. Michael’s into one such study.

Sometimes patients require surgical removal of the hypertrophied parathyroid glands. There are two major indications for parathyroidectomy in renal transplant patients: severe symptomatic hypercalcemia, usually occurring in the early post-transplant period, and persistent, marked hypercalcemia.

Summary

Hypercalcemia and hyperparathyroidism post-kidney transplant is a common condition directly related to calcium and phosphate disturbances from previous renal failure and dialysis. High blood calcium and PTH levels can lead to problems in the transplant recipient. Not everyone requires treatment for this condition, but options include medical therapy or surgical removal of the parathyroid glands for more severe cases.

References

Generic Transplant Drugs are Coming to Ontario

Most transplant patients are accustomed to taking two or three types of transplant immunosuppressive drugs for the life of their transplant. These drugs are typically changed to other types only for specific reasons which are discussed during the Transplant Clinic visit. You may have noticed, however, that over the years some of the other medications you have been taking, such as antihypertensive or cholesterol lowering drugs, were changed to “generic” versions by your pharmacies because the “patented” drugs are no longer covered by drug plans, are significantly more expensive, or are simply not available any more. For the most part, transplant immunosuppressive drugs have been spared these types of changes, but this may be different in the coming years.

Over the next year, you may be informed during a Transplant Clinic visit or over the phone that your transplant immunosuppressive drug regimen is being adjusted. This may simply involve a change in formulation, such as a twice-daily to once-daily formulation of the same drug, or it may involve a complete switch from one drug to another, within the same class or to another class. The reason specific to your case and the method for switching will be discussed. Please be assured that the Transplant Clinic is simply doing its best to adapt to a rapidly changing pharmaceutical environment, and that all changes will be made only when the nephrologist feels that there is reasonable safety involved in making the switch. It may turn out that neither the patient nor the Transplant Clinic has any other choice in the matter. More monitoring may be required afterwards.

If you wish to discuss this in advance, please bring up the topic during your Transplant Clinic visit.
Guests in the Transplant Clinic

Many times kidney transplant patients bring their spouse, child, sibling, or other close relative or friend along with them to their Transplant Clinic visit. This is of course permitted and encouraged, as long as space and time constraints for that visit permit. The advantages are that if more people hear the same information from the nurse or physician, more can be retained and implemented, and the patient may also get substantial assistance with mobility, filling prescriptions, saving time with bloodwork, etc... that might not otherwise be possible.

On the flip side, the Transplant Clinic sometimes has guests too. You may be introduced to them at the time of the initial nursing assessment, or later on when they come in accompanied by the nephrologist. These guests may include for example third or fourth-year medical students, interns, residents, fellows; pharmacy, dietician, social work or nursing students, or research or pharmaceutical representatives. In all cases you are entitled to know who they are and not permit them to “listen in” on your conversation with your nurse or physician if you are uncomfortable, so please do not hesitate to ask them if they do not introduce themselves to you right away. However, by permitting these guests to be part of your care you are helping to enhance St. Michael’s reputation as a leading teaching institution. Your confidentiality is always preserved.

Research Projects at St. Michael’s Hospital

Dr. Ramesh Prasad

The Transplant Program conducts its own research and also participates in multi-centre research by collaborating with other Transplant Centres both in Canada and abroad. You may hear about an ongoing research project at the time of your Transplant Clinic visit. You may also receive a letter or telephone call to see if you are interested. If you are asked to participate, you are by no means obliged to participate; please take your time in deciding whether a particular project is right for you. The majority of studies do not involve testing new drugs, but rather determine new ways of using existing drugs or conducting new types of non-invasive biochemical or physical measurements in transplant patients. In all cases, you will be allowed to participate only if your Transplant Nephrologist strongly feels that it is likely to be safe for you. Studies are approved by our Research Ethics Board.

A big thank-you to all who have participated in research in the past! Please contact us if you would like information on the results from a study in which you have participated. If you have any questions about transplant research, please feel free to call our Transplant Research Team at 416-867-3692.
Transplant Story – by Norman Feder

With courage, a positive attitude, unrelenting support from my wife, family, friends, and a caring and dedicated dialysis unit team at Sunnybrook Hospital, I was able to face challenges and cope with many issues during the 7½ years I spent on dialysis. With chronic disease, time takes its toll on the body and organs. A kidney transplant is not a cure, but a vastly improved treatment option for kidney chronic disease (CKD).

However, due to lengthy waitlist times, a patient’s health deteriorates, and a transplant may become a much greater risk. During my time on dialysis, it was my fervent hope and desire that one day I would be fortunate enough to receive a transplant. On August 30, 2007, at 3:00 a.m., we finally got THE CALL that a kidney was available at St. Michael’s and to “come on down”. From that moment on, it was surreal, like an out-of-body experience. It felt as when we had our babies, and it was time for the delivery. We went through the motions of getting dressed, preparing a suitcase and leaving for the Hospital, arriving at 4:00 a.m. – still thinking that it was a dream.

Following standard blood work and a series of other tests, I was wheeled into the pre-op room. While waiting, I noticed my surgeon, Dr. Pace, running down the hall shaking a small cooler to give its contents a kick-start. Lo and behold, the cooler contained my new organ! The surgeon advised my wife, Marge and son Elliot, that the post-op recovery would take some time prior to them being able to see me. Regrettably, both my short term and long term memory is rather lacking. With tubes and IVs through many orifices and parts of the body, I asked the nurse whether my wife was aware that I was out of surgery and said that I would like to see them. She contacted my wife and upon their return, were astonished that I remembered the cell number!

St. Mike’s has a four bed I.C.U. room on the Nephrology floor with nurses in attendance 24/7. In my case, only two patients were in the unit, with one nurse who monitored the patients. Having two or four patients per room can be very trying for the staff, since we all respond differently to post-op recovery, pain threshold and hospital noises. During my stay, the doctors, nurses and the follow-up renal team were second to none in the care and perseverance. It was a challenge dealing with the pain, getting out of bed and the ambulating (NO PAIN! NO GAIN). Walking really is one of the best medicines for quick recovery and recuperation. Post-op, the doctors, nurses, and the follow-up renal team were second to none. Prior to discharge, I was seen by a pharmacist and dietician, who provided guidance and the proper regimen for the medication (anti-rejection drugs to maintain proper kidney function) and diet. I was kept on dialysis for a short period until the doctors were satisfied with the progress of my new kidney.

After discharge, I was monitored frequently with blood tests and clinic visits. In time, the intervals got longer and the medication was adjusted, as required. Today, I get blood tests every 3 months and have clinic visits, every nine months. In time, longer intervals for tests and visits may occur. Adherence to the routines prescribed is crucial and one should not steer away, without consulting the doctors. The transplant kidney is precious and one should do everything in their power to keep it healthy. It is important to be a self-advocate. Ask questions and be inquisitive to find out the why, where, how and side effects from the meds. In short, be “The Master of Your Own Domain”!

It is going to be four years in August since I received a new kidney from a deceased donor, life is great and I haven’t looked back. We now have complete freedom to come and go when and where we please, on short notice. I have regained my energy and take advantage of every day. We are on the move, constantly. Before, when visiting my grandchildren, they referred to me as “Grandpa Shh”, because I lay on the couch resting and napping. Now I am actively interacting with them both physically and gaming.

An individual is not an island unto oneself. We rely on the support from family, friends and others. In particular, my wife, Marge serves in dual role, both as a “Guardian Angel” and an “Inspector General”. She keeps me grounded and is truly a care giver. We influence and affect those that surround us and the following are the perspectives of both my children’s families:

“Even though Norm put on a brave face as a dialysis patient and tried not to let it curb his lifestyle, we could see the impact it had on his energy, his stamina and overall well-being. After the transplant he is more like his old self again, full of energy and able to give all of himself to his family and everything he does. We feel so grateful that we are able to benefit from Norm’s renewed zest for life and tireless devotion to his children, grandchildren and the community”. As an active retiree, my time is spent on many endeavours. I have a vested interest in the Kidney Foundation and am involved extensively in volunteer work; peer support, planning and fund raising committees for several Patient Symposia, a big advocate for travel, I participate on panels, and most recently, I am the Kidney Foundation Representative for the Toronto Central LHIN – Regional Program Steering Committee, ensuring quality and equitable access for people living with a kidney condition, along the continuum for early detection, education, prevention, to renal therapies, inclusive of end of life care.

How can I ever thank the donor and the family for giving me this amazing gift and opportunity for a better life? I wrote a letter which was submitted to Trillium of Life to show our deepest appreciation with the hope that we can meet personally (they opted for anonymity). Donating organs is an altruistic act of courage for humanity and a true gift of life.

BE A DONOR! SAVE A LIFE!
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Inspiring Science.