Every so often we hear of inspiring stories within the transplant community. This is one such story. It was submitted by Stephanie Fitch of the Transplant Companions Program. If you want to be inspired, read on.

Dave Smith, a kidney transplant recipient, will attempt to break a world record by being the first kidney recipient to summit Manaslu, the 8th tallest mountain in the world.

He is the current president of the Canadian Transplant Association, and is a kidney transplant recipient (this spring he celebrated the 15th anniversary of his transplant). This is not Dave’s first climb. He is currently the only transplant recipient in the world to reach an altitude of 6500m, which occurred when he climbed Mount Sajama in Bolivia in 2004. This fall he aims to shatter his existing record by reaching an altitude of 8165m when climbing Manaslu.

Dave, an Edmonton native, has been involved with the Transplant Companions Program (an educational tool for pre-transplant candidates and their loved ones) for many years by participating as a patient facilitator while maintaining an active lifestyle since his surgery.

Dave will be joined by his team mates Martin Boiteau, a mountaineer and guide, and Philippe Blanchette, a fireman, both hailing from Montreal, Quebec. Going by the name Les AltiMaitres, the team’s collective goal is to raise awareness for their respective organizations and sponsors: The Transplant Companions Program, La Maison des greffés Lina Cyr (the Quebec Transplant House), and La Fondation des pompiers du Québec pour les grands brûlés (the Montreal Severe Burn Unit).

The team left for Nepal on September 2nd 2012, and will be sharing updates with us along the way. We invite you and your patients to accompany Dave on his incredible journey by following him on Twitter (@Manaslu_2012) and tracking the team’s progress through their Facebook Page: Les AltiMaitres.

Both can be accessed by visiting the Transplant Companions website at www.transplantcompanions.ca.
From the Editor’s Desk

Regular readers of Transplant Digest will probably have noticed the depth and extent to which most articles discuss various topics of interest to those with kidney transplants. It is intended to be written at a high school level. This approach has been one of substance over style, and hopefully, has been a useful service to patients that complements those provided by more reader-friendly but less content-driven publications.

If you need help understanding what is written here, ask your friends and relatives if you can. Please do not hesitate to ask questions in the Transplant Clinic as well. We will be happy to go over an article with you in the Clinic.

In this issue we discuss nausea, vomiting, and diarrhea; liver issues in those with kidney transplants, and nuts in your diet.

There is also a behind-the-scenes report about how organ donation in Ontario has increased. We report on Transplant Symposium 2012, the Youth Outreach Project, and various other educational and inspiring news items. With your ongoing support we hope to continue to bring Transplant Digest to you twice yearly for a long time to come.

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.

Announcements
It is with mixed feelings that we announce that Trixie Williams, who has been our Clinical Leader/Manager in the pre and post-transplant clinics for the last 6 years, has left St. Michael’s Hospital. We would like to thank Trixie for her leadership and vision in moving this program forward. We are sad to see her leave, but happy for her moving to the Community Care Access Program, a familiar area for her as this is one of the areas where she started her Nursing career. We wish her all the best in her future endeavours.

We would like to welcome Elizabeth Anderson as our Interim Clinical Leader/Manager. Liz comes back to St. Michael’s Hospital from the Scarborough General Hospital with an extensive experience in Kidney Care. Welcome back, Liz! We look forward to working with you once again!

Trixie Williams
Seeing the Doctor in the Transplant Clinic

Dr. Ramesh Prasad

The time spent with the physician during the Transplant Clinic is the climax, if you will, of the whole clinic experience. A lot of things have happened before then, such as blood tests and a visit with the nurse. Major decisions are made about the present and future. Advice is given. You may be examined a second time. So you may wonder: what can I do to get the most out of my visit with the doctor?

First, don’t be afraid! Doctors are human beings. Ask questions about your health, and if you forgot to bring something up with the nurse earlier, you can still bring it up with the doctor later. Don’t withhold anything. The doctor will also be happy to go over the computer screen with you to show your test results, if you wish. If you have forms that need to be filled, you can hand them in to be filled then or later. You may also be asked to consider participating in research. Again, ask questions!

In the Transplant Clinic we have different doctors on different days of the week, since our transplant population is so large. But information is freely shared within the Transplant Program. This allows for a patient to change days at will over time. It is a wonderful flexibility that few clinics can provide. You may find only a particular day of the week convenient to come, or may become accustomed to seeing one particular doctor over time. Wherever possible, we will try to accommodate your schedule and preferences for the next visit if it is not urgent. Sometimes, however, you may see a different doctor from the one you expected to see. We have found that it is much better to continue with a clinic on a particular day but with a different doctor than to cancel a clinic completely because the original doctor couldn’t make it that day. We hope you agree. While doctors’ personalities may not be identical, their access to information in the clinic is the same!

Vaccination for Kidney Transplant Recipients

It is the responsibility of all kidney transplant recipients to ensure that they are up-to-date with their vaccinations. In general, killed vaccines are acceptable for use, while live attenuated vaccines should be avoided. Please discuss your vaccination status with your family physician.

In October 2012, the Centers for Disease Control and Prevention in the United States recommended the 13-valent pneumococcal conjugate vaccine (PCV 13) in addition to the 23-valent pneumococcal polysaccharide vaccine (PPSV23) for solid organ transplant patients. Revaccination is after 5 years. It is not clear yet how this will apply to Canadian patients but you may wish to discuss this with your family physician as well.
Successful Youth Outreach Pilot Project

St. Michael’s Hospital Represents
Galo Meliton, RN, C Neph (C)

The St. Michael’s Hospital Renal Transplant Program, the Hospital for Sick Children (Sick Kids) Transplant and Regenerative Medicine Centre, and the University Health Network (UHN) Multi-Organ Transplant Program teamed up with the Trillium Gift of Life Network (TGLN) this past spring and launched a very successful youth outreach encouraging high school students to become ambassadors for organ and tissue donation.

This high school initiative pilot project was designed to convey the importance of organ and tissue donation and transplantation to youth (aged 16-19) in both the Toronto District School Board (TDSB) and the Toronto Catholic District School Board (TCDSB). The goal was to educate this audience on both the importance of organ and tissue donation and registration and speaking to their families about their decision.

Nearly 100 health care professionals from the three transplant programs as well as transplant recipients and one living liver donor volunteered their time to present alongside TGLN staff at 35 Toronto high schools. A total of 55 presentations reached more than 6,000 students between March 7th to June 6, 2012.

The overarching goals of the pilot project were:

1) To (further) increase the donor registration in the Greater Toronto Area.
2) To create one conduit of communication between those committed to a Youth Outreach Strategy within the Toronto Transplant Institute.

Metrics on the Project to Date include:

Health Care Professionals
- 96 trained volunteers
  - SickKids: 22
  - UHN: 69
  - St. Mike’s: 5

Representation by Role
- Allied Health Professionals: 45
- Physicians: 18
- Surgeons: 9
- Nurse Practitioner/Registered Nurses: 24

Pre and post presentation survey results have been analysed and they have shown a positive change in the students’ attitudes toward organ and tissue donation.

Ronnie Gavsie, CEO of Trillium Gift of Life Network, notes, “We are happy to be working with our partners to build a culture of organ and tissue donation in this province. The youth outreach program is a wonderful platform to enhance knowledge and understanding and to emphasize that assigned organ donor card no longer means you are registered. To register your consent to be an organ or tissue donor, you need to visit www.beadonor.ca and can take two minutes to register online. Do it today, you may save a life.”

With the pilot project having been so successful, the program has already moved forward with several presentation bookings for the academic year 2012-2013 and is off to great start!

From a personal perspective, taking part in this initiative, being the lead representative for St. Michael’s Hospital and facilitating and presenting sessions has been one of the most rewarding and exhilarating experiences I have had in my professional career.
The Liver in Kidney Transplant Recipients
Dr. Ramesh Prasad

We may think that the kidney is the most important organ in the body, but the liver performs more functions and is perhaps more complicated overall. It has a unique ability to grow itself again if a large part is removed, and it is very forgiving of ongoing insults to it such as from alcohol and other poisons. Monitoring your liver is an important part of your kidney transplant care, so let's take a closer look at it.

The liver's health is evaluated in depth before your kidney transplant. A few blood tests (called the AST, ALT, ALP, and albumin) are routinely checked. If they are abnormal, further tests are ordered and if necessary a hepatologist (a physician who specializes in liver diseases) is consulted. All transplant candidates get an abdominal ultrasound which looks at the liver. We often see a “fatty liver” as a reflection of excess alcohol intake or too much body fat overall, but on occasion cirrhosis of the liver, a very serious condition, is diagnosed, which may preclude a kidney transplant. There are some diseases which affect both the liver and kidney, such as hepatitis B and C, and polycystic kidney/liver disease. Sometimes, both organs need to be transplanted. In a condition called hereditary oxalosis, the “fault” lies with the liver but it is the kidney that fails. So these patients need both organs transplanted to prevent the kidney from failing again! Sometimes, gallbladder disease is reflected in liver blood tests.

The liver is the body’s “factory”. It makes multiple chemical compounds that are essential to life. Most drugs we ingest also pass through the liver. Some of the variation we see in drug exposure from one patient to the next is actually due to the differences in liver handling of these drugs. Fortunately, most drugs we use in transplant patients are not toxic to the liver.

After the transplant, the same liver blood tests are part of the routine monitoring. They are done from the same tube of blood as your kidney function tests. As with kidney function tests, it is not necessarily the absolute value but the trend over time that may be more important. You may get a call from the Transplant Office because one or more of your liver blood test results has come back as abnormal, and be requested to do more tests. Sometimes these tests can be done only at our hospital. Please take any advice you receive about your liver seriously. Obviously alcohol must be avoided, and acetaminophen (Tylenol®) should not be used in that situation either. You should also provide the names of any other medications you are taking since they may need to be stopped or adjusted, and if you are taking any herbal preparations we should definitely be informed. Infectious hepatitis (hepatitis A) can be acquired when you travel. Please consult with a travel clinic prior to trips where you could be exposed.
Organ Donation in Ontario: How we have begun to turn things around

Dr. Jeff Zaltzman
Director Transplant, Medical Director Diabetes Comprehensive Care Program,
St. Michael’s Medical Director Transplant TGLN

For many years the organ donation rate in Canada and in the province of Ontario has been quite dismal. Despite being relatively rich country, our generosity in terms of those willing to donate theirs or their loved ones’ organs after death has been wanting. One metric of organ donation rate is the number of donors per million population. While this measurement has its flaws, Canada as a country has averaged between 13-15 deceased donors per million. This is in contrast with countries such as the USA and Spain where rates of 20 per million and 30-35 per million are reported respectively. On average a single organ donor can provide about 3.6 solid organ transplants and much more in terms of tissue such as bone, corneas, skin, heart valves. In Ontario, 3 people die everyday awaiting a life saving organ for transplantation.

Prior to 2001, the groups responsible for organ donation in Ontario were fragmented, with no coordinated system in place. Traditionally some regions of the province did a good job in promoting organ donation, but this was not consistent. Then Premier Mike Harris established a committee whose task was to make recommendations as to how to try and improve Ontario’s organ donation system. As a result, Trillium Gift of Life Network (TGLN) was created in 2001. This was a branch of the Ministry of Health and Long-term care, with a CEO and a board of Directors to whom it would be accountable. This organization had a budget and developed a province wide strategic plan to deal with the inadequacy of organ donation.

Highlights of TGLN’s strategic plan over the last 10 years

1. VP Clinical operations, VP of communications and IT. Most recently a VP of transplantation.
2. Chief Medical officers of donation, whose role is to work with critical care community to foster a culture of organ donation.
3. Chief Medical officer of Transplant, with one of the roles was to develop standards for acceptable donors.
4. 24/7 on physician call for transplant suitability of donors and 24/7 physician on call support for donation.
5. Mandatory calls to TGLN from critical care units with all impending deaths, or withdrawal from life support.
6. Chart review of hospitals’ performances in terms of opportunities for organ donation. This was initially dome in the top 21 organ donor hospitals (Tier 1) in the province, but most recently expanded to additional hospitals with critical care units that have ventilator support.
7. Hiring and training of Hospital on-site organ donor and tissue coordinators, whose job it is to help support the organ donation procedure, and be front line in terms of asking families and supporting them through the process. These coordinators are able to achieve a much higher consent rate for organ donation than physicians.
8. Identification and training of critical care physicians who will promote organ donation as an important part of “end of life” care.

10. Development of an affirmative organ donation registry, whereby citizens of Ontario can agree and register their wishes to donate. TGLN staff can retrieve the registry data of a potential organ donor in the ICU. While family members are always asked about organ donation, knowing what your loved ones wishes are in advance makes the decision easier. TGLN shows that when someone has registered as a donor the consent rate for donation is 85% versus 57% if this is not known. Most recently any Ontario resident 16 years of age or over can register on line at: www.beadonor.ca. To date 22% of Ontarians have registered their desire to donate the gift of life. This varies from 13% in the GTA to as high as 44% in cities such as North Bay.

11. Concentrated efforts in areas where organ donation has been poor, such as the GTA.

12. Development of a grade 11 high school curriculum on organ donation and transplantation. This initially began in London Ontario, and now is being employed in high schools across Toronto.

13. Engagement with religious leaders. Organ donation is supported by all major religions.

14. The development of donation after cardiac death (DCD). This has been discussed in previous editions of Transplant Digest. DCD in Ontario has been a tremendous success. This began in June 2006, and to date there have been over 500 additional transplants in Ontario from DCD alone. DCD accounts for 20% of all organ donors in Ontario, and we are now amongst the top 2 or 3 jurisdictions for DCD rates in North America.

15. Reimbursing for expenses associated with costs attributed to living donors.

A few Statistics:

1. During the first 5 years of TGLN (2001-2005) there were on average 141 donors per year in the province or about 12 donors per million.

2. During the last 6 years, 2006-2011, on average there were 200 donors per year or 16 donors per million.

3. In 2011 there was a record 220 donors or 17 donors per million.

4. In 2002 there was a total of 687 solid organ transplants done in Ontario, while in 2011 that had increased to 948.

5. For the first time ever, waiting times for kidney transplants have gone down. However, there is still discrepancy based on geographic location, blood type and degree of sensitization.
Post Transplant Chat
Jennie Huckle RN, Fernanda Shamy RN, Thelma Carino RN and Imelda Lo RN

NAUSEA, VOMITING, AND DIARRHEA

1. I am getting nausea all the time. What can I do about this?
If you get nausea you may try and take Gravol® 50mg as directed, unless of course you may think you are pregnant. For some people, eating something sweet can help. Look for a fever, in which case you should see your physician right away. If not but if the nausea persists, see your physician for assessment.

2. What should I do if I vomit?
If you vomit more than once, please call the Transplant Clinic for advice. You may be required to see your family physician or go to your nearest Emergency Department since you may need to receive intravenous fluids.

3. Are the drugs causing my nausea and vomiting? Can they be changed to make this less?
Yes, some drugs may be causing your nausea or vomiting. In some cases it may be necessary to change the dose or the drug itself. You will require a clinic visit to address this issue since that can’t usually be done over the phone.

4. Will my nausea and vomiting go away eventually?
Usually nausea and vomiting will resolve once the cause is determined. Soon after the transplant nausea and vomiting are quite common because your body is still getting used to many new drugs, and the doses of these may be quite high. Be sure to discuss this during your clinic visit. If it doesn’t go away, or if you have difficulty swallowing as well, you may need a referral to a gastroenterologist.

5. Should I take all my pills when I am having vomiting?
Take your Gravol® and after 1 hour take your antirejection medications only. Have someone check your blood pressure and if it is low do not take your blood pressure medications if you have been instructed about this previously. Be sure to contact the Transplant Clinic for guidance.

6. What are the best foods to eat when I am having nausea and vomiting?
Avoid all dairy products and make certain to drink clear fluids including brothy soups. If available or possible you may take commercially prepared drinks for electrolyte replacement e.g. Gatorade®. Be especially careful not to drink too much water without taking in some salt as well. Best foods to try and eat are mostly dry foods such as toasted breads, crackers etc... If you cannot keep up with your fluid and food intake you must go to the hospital to be assessed for IV fluids. This may save your kidney transplant from damage.

7. I just vomited all my pills up. What should I do?
If you are sure that you have vomited all your pills and can see them in your vomit, you then can take Gravol® and 1 hour later take your anti-rejection medications again. Otherwise, take them again when regularly scheduled.
8. What exactly is diarrhea? I am told many times that I don't have diarrhea when I think I do.

Diarrhea generally means watery stool more than 5 times a day for 2 to 3 days. The actual definition is more than 200 grams of stool per day, but of course we don't weigh it. Keep in mind that everyone's bowel habits are different. Sometimes diarrhea is associated with cramping or blood in the stool. Ask the Transplant Clinic for guidance.

9. Are any of my pills responsible for diarrhea? What should I do when I am having diarrhea?

It is possible that some of your medications may be causing your diarrhea, especially early after the transplant, in which case you should call the Transplant Clinic right away. It is important for you to check if there are any new changes in your diet or medications. You may also have been in contact with other people who may have the same symptoms and therefore have an infection. Visit your family physician if it is severe or persistent and just as with vomiting, or if you have a fever, and make sure you are getting enough salt and fluids into your body.

10. Should I be taking extra pills when I am having diarrhea?

No, you should not take any other medication until you know the reason for your diarrhea. In fact, the dose of some your medications may need to be reduced. Don’t adjust your medicines on your own without medical advice.

11. Are there any special tests I need, like a stool sample?

Yes, it may sometimes be required that you provide a stool sample depending on your assessment by either your family physician or the Transplant Clinic, such as when an exotic infection is strongly suspected. You may also be referred to an infectious disease specialist for advice on antibiotics or anti-parasitic drugs, or a gastroenterologist for further tests such as a colonoscopy and to look for malabsorption syndromes. If you do your routine Transplant Clinic blood tests when you are having diarrhea, please let us know because it helps us to interpret the results.

12. What are the best foods to eat when I am having diarrhea?

When having diarrhea the best foods to eat are bananas, rice, apples and black tea (BRAT diet). But prevention is better than cure, so avoid eating undercooked meats or seafood. Watch out for foods that have passed their freshness date or have been left in the open.
Many transplant recipients view their new kidney transplants as an opportunity to break free from the strict diet rules of dialysis. Not having to manage the delicate balance of restricting dietary potassium, phosphorous, fluid, and sodium is one of the pleasures of transplantation. However, when considering the side effects of transplant medications which place recipients at higher risk for chronic diseases, nutrition can play a vital role in preventing cardiovascular disease.

In particular, regularly eating nuts can show a pronounced effect in helping to prevent heart disease. People on dialysis will often avoid nuts due to their high potassium and phosphorous content, but after kidney transplant, most recipients would benefit from re-introducing nuts into their daily diet. Nuts are mostly composed of monounsaturated fatty acids, which can help reduce a variety of cardiac risk factors. Nuts also contain other heart-healthy and anti-inflammatory nutrients such as fibre, vegetable protein, vitamins, minerals, polyphenols and phytosterols.

There are more than twenty-five clinical studies published where participants were asked to eat nuts daily, and then had a number of cardiac risk factors assessed before and after they started eating nuts. Participants eating nuts at least once per week had a better cholesterol profile (lower total cholesterol and LDL-cholesterol, and higher HDL-cholesterol), better blood pressure and lower markers of inflammation versus those who ate nuts less often. There was also a dose-response, with even greater improvements with eating nuts more frequently.

Epidemiological studies have all demonstrated health benefits in study participants who ate nuts frequently. People who ate nuts over four times per week in the Adventist Health Study had a 51% lower risk of non-fatal myocardial infarction and 48% lower risk of fatal coronary heart disease compared to non-nut eaters; in the Physician’s Health Study, participants who ate nuts more than once per week had a 30% reduction in fatal coronary heart disease risk. Although people who eat nuts usually also eat other healthy foods and are less likely to smoke or be overweight, these studies all corrected for these factors and highlight that all of these benefits are from the nutrients in the nuts.

Although nuts are high in calories and fat, they don’t seem to contribute to weight gain. Studies have actually shown that eating nuts contributes to a lower body mass index and waist circumference!

Almonds, walnuts and peanut butter have been studied the most and show consistently positive health effects. Whether you’d prefer to whole nuts or eating nut butters (like almond butter or peanut butter), both should help to improve your cholesterol and inflammatory markers. The majority of antioxidants in the nuts are in the skin, so you’ll have the most benefit from nuts that still have their skins. Try to stay away from salted nuts, and nut butters that contain added salts and sugars. Eating nuts every day is just one small and feasible way to help maintain your heart, and your transplanted kidney, in optimal shape for the long term.
Renal Transplant Symposium 2012: The Best One Yet
Galo Meliton, RN C Neph (C)

The fourth Renal Transplant Symposium hosted by the St. Michael’s Hospital Renal Transplant team was held on May 25, 2012 and it proved to be the best one to date. Held at the Li Ka Shing Knowledge Institute, the event was attended by close to 200 Nurses and Allied Health Professionals from a number of pre-dialysis and dialysis centers from Ontario and the GTA.

The main objective of the Symposium was to inform our referring centers’ front line staff of the new initiatives that have recently been implemented by the St. Michael’s Hospital transplant team which have positively impacted our patient population, their families and friends.

The title to the Symposium was Forging Ahead with Excellence in Patient Care. The day was appropriately started by a talk from Janet MacLean, Vice President, Clinical Affairs at the Trillium Gift of Life Network (TGLN) entitled Donation and Transplant: System Level Integration. She talked about a new web-based program called Gift of Eight Campaign, in order to encourage the public to use social media to increase awareness of the importance of organ and tissue donation.

Janet MacLean was followed by Kathryn Salvatore. She described her role in “A Day in the Life of an Organ Transplant Coordinator”. Dr. Kathryn Tinckam, Co-Director of the Histocompatibility Laboratories, gave an update on the state-of-the-art in Tissue Typing and cross matching techniques.

Dr. Jeffrey Zaltzman, Medical Director of the Diabetes Comprehensive Program (DCCP), spoke about the New Kidney Allocation in Ontario and discussed whether it’s a reality or still a dream. Dr. Ramesh Prasad who was away at an international conference gave a most interesting pre-taped update on out-of-country transplantation, focusing not only on the St. Michael's Hospital experience, but the global experience as well.

I ended the morning session with a presentation on the most recent and exciting innovative initiative the St. Michael’s Hospital Renal Transplant team has embarked on: ABO (blood group) Incompatible Living Donor Transplantation using Glycosorb® columns. St. Michael’s Hospital is the first transplant center in North America to have used these columns in living kidney donor transplantation. I also gave an update on all the other recent initiatives our program has been involved with, including the National Living Donor Paired Exchange Program.
We were thrilled to have guests from the Credit Valley Hospital Joyce Ingram and Julie Henderson, both Registered Nurses who started the afternoon by describing their Hospital’s experience in “Post Kidney Transplant Care in a Community Hospital Setting”. Dr. Jay S. Keystone, Staff Physician in the Tropical Disease Unit at the Toronto General Hospital, gave a very hilarious, entertaining and very informative talk entitled Travelling Internationally with a Transplant...Doing It Well!.

Several simultaneous breakout sessions then ensued, facilitated and presented by various members of the DCCP who addressed different aspects of pre and post transplant care.

Lastly and certainly not the least, Dr. An-Wen Chan, Transplant Dermatologist and Mohs surgeon gave an eye-opening presentation on skin cancer. His talk was entitled Not Just Another Blemish: Importance of Skin Cancer in Organ Transplant Recipients. His graphic pictures impacted the audience to have a better appreciation of the importance of counseling their patients in regard to good skin care and monitoring.

The Corporate Sponsors, as well as other invited groups such as the Trillium Gift of Life Network, the Kidney Foundation of Canada Central Ontario Branch, and the International Transplant Nurses Society Toronto Chapter were given the opportunity to have display booths during the event.

In keeping with the Greening Process at St. Mike’s, the day’s talks were sent to the attendees electronically at a later time. A big thank you goes to my co-chairs Fernanda Shamy, RN and Jennie Huckle, RN, our Corporate Sponsors, as well as to Trixie Williams, our former Clinical Leader Manager for her leadership and support, and to Dr. Ramesh Prasad, for his guidance as Program Advisor. The Planning Committee would also like thank Jacqueline Chen, RN, Francine Garraway and Sheila Buencamino for all their hard work toward the success of this event.

Although it would be quite a task topping this event, with the feedback from the attendees being excellent, the Planning Committee is encouraged to start planning another information filled event in the year 2014!!!