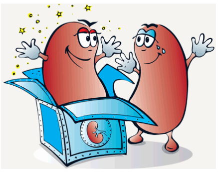
Kidney  Kronicle

Fall 2016
www.lhsc.on.ca/renal

Message from the Chair of the Renal Patient & Family Advisory Council

I am pleased to succeed Dr. George Goodlet as Chair of the Renal PFAC. George was our founding Chair and he guided the establishment of our Council over the past two years. He currently serves as Past Chairman ensuring his contribution will continue.

This year we welcome some new patient advisors and staff to Council, adding to our strength of patient experience. My goal is to continue and build on the momentum gathered with Council to date and to develop new ideas to help kidney patients cope with the disease. To that end we will work to be inclusive across the geographic region served within the LHSC Renal Program.

The strength of Council grows with kidney patient involvement. We encourage your involvement through occasional patient surveys, discussions with patients at the dialysis units, and direct input volunteering as a Patient Advisor. Also, we are finalizing a Patient Resource Centre at the Westmount clinic that aims to provide helpful advice to patients and provide an on-site opportunity to provide feedback.

I encourage all patients to take note of the activities of council using our website and by picking up a copy of The Kidney Chronicle at the clinic or waiting areas at all dialysis units. Submitted by Fred McInnis, Renal PFAC Chair

It's Flu Season!!

We asked JulieAnn Lawrence, a Nurse Practitioner in the Renal Program about the flu shot and other suggested vaccines for patients with kidney disease.

- Flu Vaccine: All patients and staff should get the flu shot. Talk to your doctor if you are allergic to the vaccine.
- The Flu Shot will NOT make you ill as it's a KILLED/DEAD virus. However, if you are feeling unwell, it is suggested to defer getting the flu shot until you are feeling better.
- You can get a flu shot from your family doctor or most pharmacies.
- Pneumococcal Vaccination: This vaccination helps to protect against lower respiratory tract infection/ pneumonia, and is given every 5 years. It is recommended for all adults 65 years or older, but those aged 19 to 64 who have a chronic illness such as kidney disease, are also at increased risk for pneumococcal disease. Ask your kidney doctor or nurse practitioner for more information.

Stay tuned for more information on Varicella and the Shingles vaccination in the next newsletter.

Living Donor Kidney Transplants

In 2015, 101 kidney transplants were performed at London Health Sciences Centre. 25% of these kidneys were donated by living donors. There are many reasons why a transplant from a living donor may be the best option for a patient. Transplant outcomes are generally better with kidneys from living donors than from deceased donors. Outcomes are best for patients who receive a transplant before needing to start dialysis. With careful planning, a patient can avoid the need for dialysis and go straight to transplant with a kidney from a living donor. Living donor transplants can be arranged to optimize timing for both the donor and recipient. While some living donors are related to the recipient, they don't have to be. Living donors can be siblings, parents, children or other relatives. A donor can also be a spouse, relative through marriage, co worker, or a member of the recipient's community.

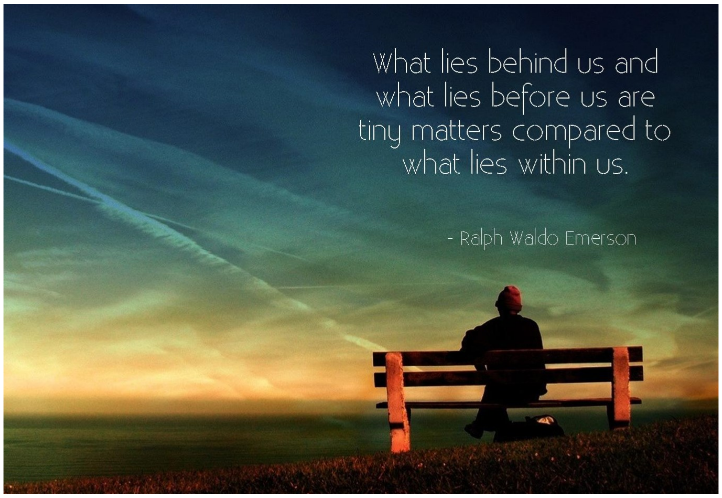
Approaching a potential living donor can seem difficult. The brochure 'Finding a Donor' was created to assist potential transplant recipients in reaching out to potential donors. You will find information about who to approach and ideas for getting the word out that other recipients have successfully used in the past. You can find this brochure and more information about living donors and kidney transplantation in the new educational materials created by the Living Kidney Donation Program at LHSC. They can be found in the waiting rooms at your dialysis unit or clinic, or ask a staff member for a brochure. You can also find the materials online at:

www.lhsc.on.ca/livingkidneydonation

For more information contact:
Living Donation Program
519 685-8500 ext. 33552
livingkidneydonation@lhsc.on.ca

Living Donor Information

- Donors can live normal healthy lives with one kidney.
- Donors must come forward voluntarily, and must not be under any pressure or forced to donate.
- Donors must be in good physical and emotional health and give informed consent for the surgery.
- Donors must be at least 18 years of age but no strict upper age limit for donors.
- At any step in the process, donors can choose not to proceed.



Interview with Home Hemodialysis Patient Caroline Powers

Tell us about yourself.

I'm 65 years old and retired after having worked as a respiratory therapist at LHSC for 20 years. I've also been a potter, school bus driver and an animal health technician. I was diagnosed with Henoch Schoenlein purpura in 2000. Initially it was hoped to be a self limiting disease, which would run its course and go away but this was not to be. Over the course of the next six years my health gradually deteriorated until I went into renal failure in 2006. My husband Greg wanted to donate a kidney but unfortunately we were not a match. This was before the National paired exchange program was available in Canada, so Greg and I asked OHIP if we could go to the paired exchange program at Johns Hopkins Hospital in Baltimore, Maryland. After a long battle, including an appeals tribunal, OHIP were ordered to fund our trip to the states. That kidney lasted for seven years. It was during that time that we retired and travelled to England, Ireland, Alberta, British Columbia, and Florida. I've been back on dialysis for eight months now. I'm on the transplant list, including the highly sensitized patient list. My daughter wants to donate a kidney this time, and together we are being included in the paired exchange program in Canada. I'm on nocturnal home hemodialysis and the wait for another transplant goes on.

How long have you been on dialysis?

I have been on hemodialysis for eight months since a failed transplant in February 2016. Prior to my transplant in 2009 I was on peritoneal dialysis for 2 1/2 years.

How did you decided to do dialysis at home?

I decided on dialysis at home because I wanted the autonomy and convenience. I am able to dialyze when it fits my schedule without spending time travelling to a dialysis centre.

Can you share some advantages and difficulties of home dialysis?

Aside from having the freedom to dialyze when I choose, I like feeling that I play an important role in my own health care. Although there are some great advantages to dialyzing at home there are certainly challenges as well. It took weeks of training to feel confident setting up my dialysis machine and running it on my own. You take on the responsibility not only of dialysis but of setting up and cleaning your machine, organizing and ordering all the supplies needed, doing your own blood work, giving medications and troubleshooting when things go wrong. I am continually supported by the great nurses at the home hemodialysis centre at Westmount Mall and also by my husband Greg who took the training with me and is a constant partner in dialysis.

How do you feel physically after having home dialysis compared to dialysis in the hospital?

For the last two months I have been doing nocturnal hemodialysis. I found dialyzing while you sleep to be difficult to adjust to but I'm finally getting the hang of it. I now dialyze more frequently and for much longer periods of time than I did when I was going to the hospital. Consequently I am feeling very well. I have more energy and a much better appetite. I've gained a bit of weight and I'm stronger and healthier than I have been in ages.

Can you travel now that you are on home dialysis?

Travelling on hemodialysis is not easy although it can be done. Greg and I went to salt Spring Island in British Columbia last spring to visit with our children and grandchildren. It took a tremendous amount of organization; finding the centre in BC that would take me and answering all their questions. They needed lots of information from the dialysis centre here and I had to see a nephrologist in BC prior to starting on dialysis. Travelling on peritoneal dialysis is much simpler although it takes a fair amount of organization as well. You take your peritoneal dialysis machine with you and have all the needed supplies delivered to your destination before you arrive. You then continue dialysis as usual.

Do you have any advice for renal patients who might be starting dialysis soon or considering a switch to home treatments?

If you are starting on dialysis soon I wish you luck. Gather all the information you can around the different types of dialysis. Talk to people on dialysis about their experiences. Decide what's most important for you. Is it the autonomy and freedom of dialyzing at home, or the ability to travel easily? Would you prefer to go to a centre and have the healthcare team take responsibility for your care?

The Renal PFAC thanks Caroline for sharing her encouraging story!

LIVING A HEALTHY LIFE

Do you have an ongoing health condition such as diabetes, arthritis, lung, kidney, heart disease or any other conditions?

Do you struggle with making changes to improve your health?

South West
Self Management
Program
Improving your health, together.

The Southwest Community Care Access Centre offers a free 6 week "Living a Healthy Life" program for individuals and their families living with Chronic Health Conditions. Go on-line or call to get more information and to register for an upcoming workshop.

www.swselfmanagement.ca
info@swselfmanagement.ca
519-421-5691 or 1-855-463-5692

Several workshops are starting in January at various locations around the city of London, as well as Strathroy and Woodstock.
Visit website for more information!

Kidney Friendly Apple Enchiladas

Makes 6 servings

Ingredients:

1 21-oz can light apple pie filling

6 8-inch white flour tortillas

1 teaspoon ground cinnamon

1/3 cup non-hydrogenated margarine

½ cup white sugar

½ cup brown sugar

½ cup water

Directions:

Preheat oven to 350 F.

Spoon Fruit evenly onto all tortillas. Roll up tortillas and place seam side down on lightly greased 8” x 8” baking pan.

Combine margarine, sugars and water in a medium sauce pan. Reduce heat and simmer, stirring constantly for 3 minutes.

Pour sauce evenly over tortillas; sprinkle with extra cinnamon on top if desired.

Bake for 20 minutes.

Note: Prepare diabetic version by substituting with diabetic sweetener.

Include 1 serving (1 enchilada) in your meal plan as:

1 Fruit & Vegetables

7 Others

2 Grains & Starches

November is Falls Prevention Month!

Cathy Litwin from the LHSC Patient Safety Office has provided us with 10 tips to reduce your chance of having a fall:

1. Slow down and take time to be safe.
2. Be physically active for a total of 30 to 60 minutes most days.
3. Have your vision and hearing checked regularly.
4. Discuss your medication and supplements with your doctor and pharmacist.
5. Eat a healthy balanced diet recommended by your renal dietitian, and limit your alcohol intake.
6. When walking outside, be aware of your surroundings and watch where you step.
7. Use safety equipment such as canes, walkers, grab bars and rubber bath mats.
8. Wear non-slip footwear that fits well and seek treatment for foot problems.
9. Use a night-light and keep a flashlight by your bed.
10. Complete a home safety checklist available online or from your health care provider.

1 in 3 seniors fall every year; the key is to stay active to improve balance and strength with at least 30 minutes of activity 5 days a week, review medications with your Doctor and/or pharmacist, and visit your eye doctor yearly. Be aware that there are medications that can increase one's risk for falling. Post dialysis, blood pressure may drop when coming from a lying, to sitting to standing position. It is important, that one gets up slowly and sits for around 5 minutes prior to standing.

Visit findingbalanceontario.ca for information!

The Renal
Patient & Family
Advisory Council
Sends
You & Your Family
Season's Greetings
&
Warm Wishes
for a
Happy New Year
in 2017!

I don't care what day it is.
Four hours is four hours.

??DID YOU KNOW??

The LHSC Renal Social Work Group has worked in partnership with the London Health Sciences Foundation and the Nephrologists to establish the **Renal Patient Assistance Fund**. This fund provides financial assistance for kidney patients who are assessed as having short-term, emergency financial strain as a result of their kidney disease.

To access financial assistance through the Renal Patient Assistance fund a referral must be made to your renal social worker. The social worker will assess the need and specific situation to determine eligibility for funding in accordance with the guidelines established for the fund.

For further assistance please contact your renal social worker who can assist in accessing financial supports that meet your specific need.

renal P.F.A.C.
PATIENT & FAMILY ADVISORY COUNCIL
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