



Spring/Summer 2019 Issue

Kidney Patients Rally Against Changes to Out of Province Medical Care Coverage

Dialysis patients Emma Klotz and Bonnie Field have spent the past weeks bringing attention to cuts surrounding out of country dialysis treatments. Recent cuts to OHIP announced by the Ontario Government mean dialysis patients will no longer be partially reimbursed for dialysis treatments received outside the country. Under the previous funding if a patient paid for a dialysis treatment received outside of Canada, OHIP would reimburse \$210 per treatment. Treatment prices outside of Canada can range in price from \$300 to \$700 per treatment depending on location. Dialysis patients are unable to purchase travel medical insurance to cover the cost of dialysis treatments outside of the country because renal failure is considered to be a pre-existing condition. This means the total cost of out of country dialysis lies with the patient.

Emma and Bonnie have been advocating on behalf of renal patients in the London area to readdress these cuts, which would come into effect October 1, 2019. A press conference was held on May 11, 2019, where Bonnie and Emma teamed up with London North Centre MPP Terence Kernaghan to spread the word about the impending cuts. At the provincial level, the Ontario Renal Network, who provide bi-partisan advice to the

www.lhsc.on.ca/renal

Government of Ontario on how renal services are delivered have also pointed out that the proposal suggests people traveling outside of Ontario can obtain private travel insurance to cover the cost of medical emergencies, however there is no private insurance available for dialysis treatments.

Recently the matter was discussed in Ontario parliament where Ontario Minister of Health, the Hon. Christine Elliott suggested that after consulting with the public this matter has been brought to the Government's attention and they will reassess the situation in the future.

For more information about Bonnie and Emma's work, please view the press release from the [Blackburn News OHIP CHANGE](#), and The Star article [Dialysis Patient Cry Foul Over dialysis coverage](#).



Photo courtesy of Miranda Chant, Blackburn News, May 10, 2019

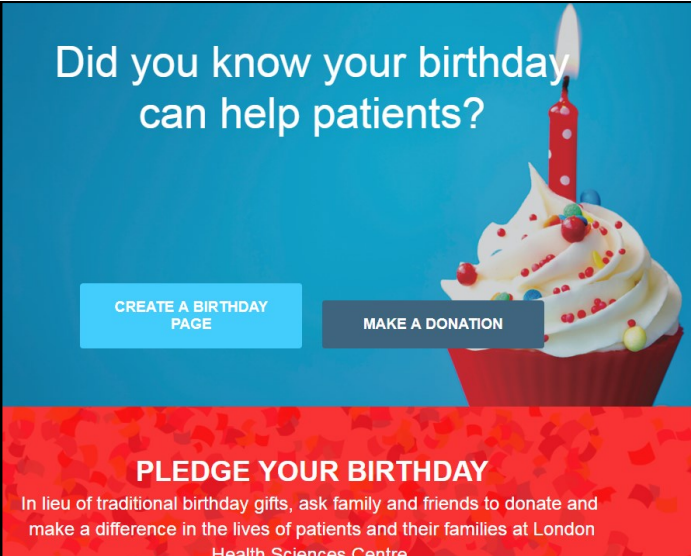
The London Health Sciences Foundation Birthday Fundraising Page

The London Health Sciences Foundation has created a unique way to raise funds for London Health Sciences Centre and the Renal Patient Assistance Fund by creating a “Birthday Fundraising Page”. Users can self-create a birthday fundraising page, and ask their friends and family via social media to donate to the Renal Patient Assistance Fund instead of purchasing traditional gifts.

Users can also become monthly donors, honour someone or place memorial donations via the web page.

To create your fundraising page visit the London Health Sciences Foundation web page at www.lhsf.ca, click on the Ways to Give Button, then select Celebrate. You can sign-in using your Facebook login, or create your own account. Once you set up your goal, be sure to select Renal Patient Assistance Fund as where you would like to direct your donation. Once your page is created share on your Facebook page, Twitter account and via email with all of your friends and contacts to start raising money!

A great way to raise money for Kidney Patients at LHSC!



Did you know your birthday can help patients?

CREATE A BIRTHDAY PAGE

MAKE A DONATION

PLEDGE YOUR BIRTHDAY

In lieu of traditional birthday gifts, ask family and friends to donate and make a difference in the lives of patients and their families at London Health Sciences Centre.

Bringing Healing into Focus at Schulich Medicine & Dentistry, UWO

What does healing look like? Using photography to document their lives, dialysis patients are helping researchers and clinicians at Western University learn more about resiliency in the face of diagnosis and chronic disease.

Dr. Chris McIntyre, Director of the Lilibeth Caberto Kidney Clinical Research Unit, in collaboration with the Visual Arts Department at Western University, embarked on a novel research study in 2017 in order to gain a better sense of the quality of life for people on chronic hemodialysis treatment and to better understand how they respond to treatment through imagery. Since enrolment began in the spring of 2017, 37 participants have been involved in the Renal Community Photo Initiative creating approximately 1500 images, and counting. The project allowed for a unique approach with the creation of an ongoing community of engaged patient partners living with kidney disease who have not only generated the amazing images but are helping to direct this visual approach.

This project has been funded through the generosity of an anonymous donor to Western University. Schulich School of Medicine and Dentistry, Western University, became interested in this research and offered to work with Dr. McIntyre and the research team to design a website in order to share information about the study. This website was launched on Tuesday, May 7th and can be found at:

<https://www.uwo.ca/projects/renal/>
Contributed by Cindy House, Research Coordinator



Learning Corner: Some Common Medications for Hemodialysis Patients

PHOSPHATE BINDERS: Many dialysis patients take medication called “phosphate binders”. Phosphate is a substance found in the body that comes from the food we eat. Healthy kidneys normally remove extra phosphate and pass it out in urine. Phosphate is not removed very well even with dialysis and it builds up in the blood. Over a period of time excess amounts of phosphate in the blood can cause problems such as itchiness, red eyes, painful joints, bone disease and heart problems. Phosphate binders are taken to help keep extra phosphate from building up in your body. There are different kinds of phosphate binders such as calcium carbonate (Tums® chewable tablets or Calcium Carbonate tablets), Sevelamer (Renagel®) and lanthanum (Fosrenol®). They must be taken with your meals and sometimes snacks. By keeping your phosphate levels low you are helping prevent bone problems. Take your binders every day as instructed.

IRON: Iron helps your body make red blood cells. You may need to take iron pills but most people on hemodialysis receive iron intravenous during their dialysis treatment. If you are taking iron pills these are usually taken as 2 or 3 pills at bedtime. They should be taken exactly as instructed. They should not be taken at the same time as your phosphate binders.

ERYTHROPOIETIN OR ARANESP:

Erythropoietin, also known as EPO, is a substance normally made by the kidneys to help the body make red blood cells. Many dialysis patients take EPO in order to help raise the level of red blood cells in the blood. If you do not have enough red blood cells you can become anemic. Anemia can make you feel tired and have decreased energy. Aranesp is a form of EPO that is given intravenously to people on hemodialysis during their dialysis treatment.

NEVER TAKE ANY MEDICATIONS WITHOUT FIRST TALKING TO YOUR DIALYSIS NURSE, DOCTOR OR NURSE PRACTITIONER!

Any medication should be taken with careful guidance. This is especially important in people who have renal failure since there are many medications that are cleared from the body by the kidneys. Your dialysis health care provider will choose special medications and dosages for your needs. If you are prescribed a new medication, please bring the bottle in to your appointment and show your nurse. They will check to make sure that the drug and dose are safe for you. If you see a new doctor in a walk in clinic or the Emergency department, let them know that you are on dialysis and ask if the medicine they are prescribing is safe for you. It is also a good idea to let your community pharmacy know that you are on dialysis. They can double check your medication doses as well.

Did you know the LHSC Renal Program has its very own public website for patients and families?

To access the website go to:

www.lhsc.on.ca/regional-renal-program/welcome-to-your-website

Topics found on the website include:

Education about kidney disease and its causes

Information about treatment options for kidney disease

Videos of real kidney patients sharing their story and discussing treatment options

Information about adjusting to life on dialysis

Information about the Renal Patient and Family Advisory Council

Information about team members responsible for your care

Contact information and directions to departments within the program

The Renal Patient Website has been developed as a resource for you, based on the input of patients just like you who have made or who are making the journey through treatment. Access the website often, and always ask questions at your healthcare visits, and keep notes. This will help you along the way of your kidney care journey!

Peritoneal Dialysis Supporting Long Term Care



The Peritoneal Dialysis Unit celebrated having their first patient supported through a long-term care facility just outside of London in Komoka, Ontario. Country Terrace is the first long term care facility in the SW LHIN to receive Ministry of Health approval to support residents in their facility requiring ongoing peritoneal dialysis treatment. For patients, this eliminates the burden of traveling to hospital for their dialysis care. The Regional Renal Program continues to work with long term care facilities throughout the region in order to expand access to peritoneal dialysis care in long term care homes. Way to Go Team!!!! The Renal PFAC salutes your efforts in patient centred care!!

Southwest Regional Renal Program Director Janice McCallum Retires



London Health Sciences and Southwest Regional Renal Program celebrated a fond farewell to its Program Director Janice McCallum on Sunday June 2 at the Westhaven Golf and Country Club. Janice grew up in Saskatchewan and completed her initial Nursing education at the University of Saskatchewan in Saskatoon. Her earliest nursing jobs were in Orthopedic Surgery and the Emergency Department. After moving to Ontario in the late 70's she completed a Master of Science in Nursing degree and taught Nursing at UWO for two years. Her first management role began at University Hospital 38 years ago and she has held various levels of management positions in the areas of Cardiac care, Clinical Neuro Sciences, the Emergency Departments, Medicine Inpatient and Ambulatory areas, Family Medicine, Geriatrics, Palliative Care and Renal. Janice joined the Renal Program in 2011. During her time in the renal program Janice has been passionate about person centred care, and incorporating the patient and family voice into the

patient experience. Her commitment towards seeing patients as true partners has been demonstrated by supporting the creation of the Renal Patient and Family Advisory Council (PFAC) and providing the backing needed to maintain the council. The Renal PFAC provides a direct avenue to program leaders for patients and families to provide feedback, and with Janice's support there are now patient and family advisors embedded onto all of the renal programs committees and working groups, including the renal executive which act as the decision making body of the program.

Current chair of the Renal PFAC Bonnie Field had a few nice words to say about Janice's time with the Renal Program and her commitment towards including renal patients and families as partners. "Without Janice advocating for patients our Patient and Family Advisory Council would not exist. She has been open to including patients in staff committee meetings, new initiatives and providing them with education and speaking opportunities. Her greatest contribution to patients has been her willingness to give of herself by attending all of our advisory meetings. What a wonderful opportunity it has been to have the ear of the Director of the Renal program."

The Renal Patient & Family Advisory Council has largely been successful due to Janice's commitment and vision, and the members would like to wish Janice every happiness in her retirement.

Crumbled Goat Cheese Pasta Salad

Contributed by LHSC Renal Dietitians

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

- 1 Meat & Alternatives
- 1 Grains & Starches
- 1 Fruits & Vegetables

Ingredients:

- 4 cups of cooked pasta
- 2 small red peppers, chopped
- ½ cup red onion, chopped
- 20 spears of steamed asparagus cut into small pieces
- ½ cup crumbled goat cheese
- ½ cup balsamic vinegar
- 1 tbsp Dijon mustard
- ½ cup coarsely chopped basil



Directions:

1. In a large bowl combine cooked pasta, red pepper onion and asparagus.
2. In a small bowl mix together goat cheese, vinegar, Dijon mustard and fresh basil.
3. Pour dressing over pasta and mix well. I find it works well if the pasta is still warm when dressing is added to it, so make the dressing while the pasta is cooking and then add to pasta once drained.



**Newsletter brought to you by the
Renal Patient & Family Advisory
Council at London Health Sciences
Centre**