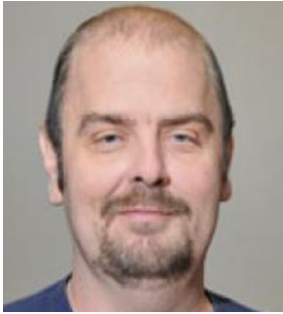


MESSAGE FROM OUR PFAC CHAIR



I have been a patient in the renal program since the age of 19. I started hemodialysis the first time in 1999, and

had my first kidney transplant in 2001 which lasted 9 years. I did a further 4 years of hemodialysis and received another kidney transplant in September 2014.

I decided to join the PFAC in 2014 because I think patient and family centered care is very important to

help and educate patients, families and staff in the renal program. I am very thankful for all the staff, doctors and nurses that I have met or crossed paths with. I am looking forward to collaborating with our program and developing new staff relationships over the course of my next 2 years as chair of the Renal PFAC.

I would like to extend a very special thank you to Janice McCallum, now retired Director of the Renal Program and Angela Andrews, previous Facilitator of the Renal Patient and Family Advisory Council. Their hard work

and dedication to the council over the last 5 years is inspiring.

I would like to extend a warm welcome on behalf of the Renal PFAC to Ashley Roberts, (PFAC Facilitator), Lesley Pringle (Renal PFAC Manager) and April Mullen (Director of the Regional Renal Program).

Lastly, I would like to extend a very special thanks to our past chair, Bonnie Field for all of her hard work and dedication to the renal patients and program. Bonnie works continuously to make sure that every renal patient has a voice. Don Smith

LIVING A HEALTHY LIFE WORKSHOP SERIES

Are you living with or caring for someone with heart disease, diabetes, high blood pressure, arthritis, osteoporosis, kidney disease or other chronic conditions?

Studies have shown that people who learn more about self-management are more likely to access the right care and are more confident about managing on their own.

JOIN US FOR THIS FREE PROGRAM

Topics include:

- Dealing with difficult emotions
- Healthy eating
- Communicating with your health care providers
- Getting active safely
- Breathing better
- Managing pain and fatigue
- Positive thinking and visualization
- Goal setting and problem solving
- And more

Workshops are available this spring across Ontario

For further information and registration visit:
www.swselfmanagement.ca



Camp Dorset is a beautiful resort located on Deer/Raven Lake in Haliburton. It is a unique facility that allows Ontarian's with kidney disease the opportunity to spend time with their families at a lakeside cabin while being able to receive dialysis on the property. There is a large meeting hall, swimming pool, tennis courts, canoes and more on the property.

ASK YOUR SOCIAL WORKER FOR AN APPLICATION FORM.

UPDATES FROM THE RENAL COMMUNITY PHOTO INITIATIVE

In 2017 researchers, under the guidance of Dr. Chris McIntyre, and in collaboration with the Visual Arts Department at Western University, wanted to better understand what gave some dialysis patients the resilience to remain hopeful, outward looking and enjoying a rich life, while at the same time healing. They gave dialysis patients different types of cameras to document their lives outside the dialysis unit in order to glimpse into their lives and better understand the healing journey.

Since beginning, thirty-nine people took more than 1,500 photos providing a wealth of information for the researchers and clinicians to learn more about resiliency and the redefinition of one's self in the face of diagnosis and chronic disease. Recent activities to raise awareness about this study and importantly about living with kidney disease were highlighted in 2019 on the Schulich School of Medicine and Dentistry website, on the CTV London evening news and on related blogs. These can be found on the following links:

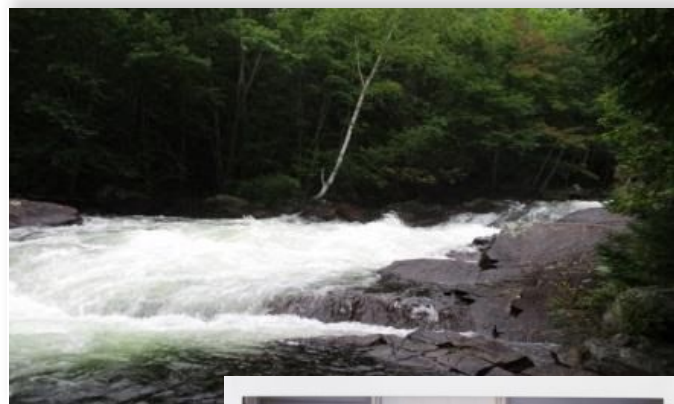
<https://www.uwo.ca/renalcommunityphotoproject/>
<https://london.ctvnews.ca/photo-project-documents-patients-coping-with-life-of-dialysis-1.4421755>

<https://homedialysis.org/news-and-research/blog/309-bringing-healing-into-focus-the-renal-community-photo-initiative>

Lately, the research team received approval to involve additional study participants. These people include those who have been diagnosed with chronic kidney disease, those using other dialysis modalities (home hemodialysis and peritoneal dialysis) and the kidney transplant population. The research team is actively recruiting participants. If you are interested in learning more about the study or participating, please contact Cindy House, Clinical Research Coordinator, (519)685-8500, ext. 34769.

Future opportunities to raise awareness about living with kidney disease are on the horizon including banner displays, World Kidney Day events in collaboration with the Kidney Foundation and partnerships with local companies who have an interest in this area of healthcare.

The images on the right are some of the photos taken by dialysis patients as part of the project.



TAX TIPS FOR DIALYSIS PATIENTS

Each year during tax season The Kidney Foundation prepares general tax tips for people who are on dialysis or have had a kidney transplant.

The income tax assistance most often used by people with kidney disease are the Medical Expense Tax Credit and the Disability Tax Credit. These are non-refundable tax credits that reduce the amount of income tax you owe.

MEDICAL EXPENSE TAX CREDIT

You can claim eligible medical expenses that you or your spouse or common-law partner paid for:

- Yourself
- Your spouse or common-law partner
- Your or your spouse's or common-law partner's children who were under 18 years of age at the end of the tax year.

You can claim eligible medical expenses that you, or your spouse or common-law partner paid for in any 12-month period ending in 2019 and did not claim in 2018.

Common expenses for people with kidney disease that can be claimed are travel, meal, vehicle, accommodation, home hemodialysis machine, organ transplant, prescriptions and

medical devices. Details of the requirements for these claims are listed on the Kidney Foundation website listed below.

DISABILITY TAX CREDIT

The Disability Tax Credit is a non-refundable tax credit which helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay. Dialysis is a life-sustaining therapy that meets the criteria for this credit. The credit will reduce your income tax payable if you qualify.

It is recommended that all dialysis patients apply for the Disability Tax Credit. Your renal social worker can help you with the paperwork, if needed. The application is easily completed and there is no need for a private company to assist. Further information is provided on the Registered Disability Savings Plan and additional tax assistance measures at:

<https://kidney.ca/Support/Resources/Tax-Tips>

VOLUNTEER TAX PREPARATION CLINICS

Volunteers trained by the CRA are available to help you complete your return. The program is designed to help low-income people with simple tax situations. To find a tax preparation clinic in your area call 1-800-959-8281.

WELCOME DR. CONNAUGHTON TO LHSC NEPHROLOGY PROGRAM



Dr. Dervla Connaughton has been appointed as Assistant Professor in the Division of Nephrology, Department of Medicine at the London Health Sciences Centre. She is also the inaugural Eugen Drewlo Chair in Kidney Research and Innovation at the Schulich School of Medicine & Dentistry, Western University.

Dr. Connaughton's research focus is to discover the underlying genetic cause of kidney disease in patients and families with inherited kidney disease. Worldwide, the use of genetic technologies is rapidly increasing and is adding to our understanding of the cause of genetic disorders. Dr. Connaughton will run a weekly Genetics Kidney Disease Clinic where she hopes to provide patients with genetic kidney disease the opportunity to avail advanced genetic analysis techniques to help diagnose and treat all forms of genetic kidney disease.

PATIENT EXPERIENCE WEEK

Patient Experience week is an annual event to celebrate healthcare staff impacting patient experience everyday.

Wednesday, April 29 2020
10:00am – 2:00pm
Victoria Hospital,
E7-002 (Zone E, 7th floor, room 002)

An opportunity for all Patient and Family Advisors to gather for a group discussion, social and celebrate award winners.

Lunch will be provided
 Open Forum + Social + Awards Ceremony

REGISTER NOW
email: patientexperience@lhsc.on.ca

DO YOU LOVE TO TRAVEL? ARE YOU A FREQUENT FLYER?

As of January 1, 2020, the Ontario Health Insurance Plan, (OHIP) will no longer cover any portion of out-of-country medical expenses other than dialysis treatments.

Whether you're headed on a short getaway or an extended vacation, this change means that it is more important than ever to make sure you're protected from the unexpected costs of a travel and/or medical emergency. It is important to shop for travel insurance before you leave the country.

Before you buy travel insurance remember:

- **Build travel insurance into your travel plans.** Keep in mind that buying travel insurance has to be done in your home province and before you leave. You can even buy it right from the departure lounge! As you start planning your next vacation, just add it to your to-do list.
- **Be honest.** It's so important to answer any insurance questionnaire accurately and to disclose things like pre-existing conditions. This will ensure you have coverage suited specifically for you.
- **Don't base your decision on price alone.** Look at what coverage is best for your needs



and consider all different types of plans and level of protection. The provincial government's cancellation of OHIP's out-of-country medical coverage means it's more important than ever to make sure you're travelling insured.

For dialysis patients, as of January 1, 2020, the Ontario Renal Network, part of Ontario Health, launched a new program to provide patients with

reimbursement for out-of-country hemodialysis. The details of the new reimbursement program are now available at:

www.ontariorenalnetwork.ca/en/kidney-care-resources/living-with-chronic-kidney-disease/about-dialysis/out-of-country-reimbursement.

This page includes information about the program as well as the new Out-of-Country Hemodialysis Claim Submission Form that patients will need to submit.

Reimbursement rates remain the same, at up to \$210 for each hemodialysis treatment received by Ontario patients outside of the country.

As information, the cost of dialysis at all Davita Dialysis centres across the U.S. is \$330 (U.S. funds, physician fees and extra medications not included).

LONDON HEALTH SCIENCE IS COMMITTED TO CARING FOR PATIENTS

One of the ways LHSC is seeking to provide patient care is by giving patients and their families a voice in their care. To that end, the hospital has brought together kidney patients and family members and some staff to sit on a volunteer council called 'The Renal Patient and Family Council.'

"Patients Supporting Patients" is a growing component of health care. Shared patient experiences improve care and help patients understand and take charge of their own health care plans.

Communication amongst patients is a proven method for identifying and carrying out meaningful changes in health care procedures and standards. At LHSC, the Renal Patient and Family Advisory Council (RPFAC) functions to identify ways and means to improve kidney care through direct feedback from patients. The issues, strengths, and common patient concerns fuel the activities of YOUR Council. In turn, your Council proposes suggestions and solutions to health care

professionals and administration to achieve desirable change.

The members of the Advisory Council represents you and they need your input. You may hear from the Council asking for information and feedback. Please help us support you by providing such input including things that are being done well and also areas that could be improved in caring for your kidneys.

The ongoing work of Council requires patient volunteers as we intend to rotate membership on the council to provide a broad and current range of input. Your positive response to requests for participation in regard to a specific task or council membership would be most welcome.

If you would like to volunteer, have something you would like to share or questions about the Advisory Council please email renaladvisor@lhsc.on.ca or call 685-8500 Ext 34411 You can get more information about the Advisory Council on the new LHSC website at www.lhsc.on.ca/renal