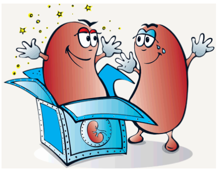
Kidney  Kronicle

Spring 2015

Introduction From The Editor

Our Chairperson, who would usually write the introduction to the Newsletter, is enjoying himself in France, so I, as editor, will take on the task for this edition. Neil Johnson, the Vice-president at London Health Sciences Centre (LHSC) responsible for renal services, has approved funding for a mail out to all registered patients being served by LHSC, in any capacity involving chronic kidney disease.

The Renal Patient and Family Advisory Council (RPFAC) has a very limited budget and we can't count on being able to mail our newsletter each issue. If you are interested in receiving the Newsletter and have an email account, you could send Angela Andrews an email at renaladvisor@lhsc.on.ca and ask to be placed on an electronic distribution list.

There is no charge for this service. We plan to publish quarterly.

The RPFAC continues to be looking for interested patients and (especially) family members to join our Council. If you or a family member is interested in becoming involved, please contact Angela Andrews at 519-685-8500, extension 34411, or email her at renaladvisor@lhsc.on.ca. Angela will send more information.

We welcome any comments on the Newsletter and will strive to make it interesting, informative and enjoyable each issue.

Michael Hermiston
Editor of the Kidney Kronicle

Council Activities Update

1. Council continues to meet monthly. Activities of Council are largely aimed at conditions that affect patients at all levels of treatment. Some notable areas of Council involvement are as follows: council members attended and participated in 'vital behaviors' workshops conducted by the Kidney Care leadership, which enable LHSC renal staff to focus on interactions with patients and families, and ways to enhance patient services. Feedback from these workshops was very positive and clearly demonstrated the willingness of staff to embrace opportunities to improve patient engagement.

2. The Transportation Task Group identified a number of patient transportation issues, mostly related to Para transit. A meeting with the service provider is planned and practical solutions will be sought. The group is pleased to welcome the assistance of the Kidney Foundation of Ontario in this activity.

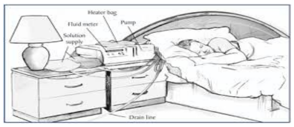
3. The Feedback Task group developed a plan to conduct patient feedback fora [plural forum] in the coming months. Notifications regarding the location and times will be posted in advance at all renal locations. These fora will provide an opportunity for patients to input ways to improve patient services.

4. The Resource Task Group, with the assistance of a staff librarian, is working to consolidate and streamline the display and availability of patient resource materials and services. The vision is to create the concept of a kiosk display containing information vital to patient care which is easily identifiable at the entrance and waiting areas of the renal units.

5. Patient Story Telling - several Council members have shared their stories about the experience and effects of kidney disease on their lives and the lives of those around them. Some powerful themes emerge from this ongoing component which will serve to inform both the patients and staff. Renal administration have strongly encouraged and supported this Council's endeavours.

Report submitted by: Fred McInnis.

Travelling with PD



Like most people, until I had to decide on which dialysis method to use, I knew only about hemodialysis. When I discovered that peritoneal dialysis (PD) would allow us to continue to travel, the choice was easy.

In PD, fluid (a sugar solution) goes into the abdomen and draws fluid from blood vessels into the abdomen and is then drained. Normally I dialysed at night using a machine (cycler) but there is another method which uses gravity and is done during the day (twin bags). Which method to use depends on the kind of travel and what you want to do during the day.

The easiest way to travel is by car because this means that the fluid goes with you. How far you can go depends on how much fluid you can get in the car. For longer trips the fluid can be delivered to your destination.

Since the cycler can be transported, it can go in the car with you and it only needs to be plugged in on arrival (110 VAC). We did this to go to Algonquin Park to hike. By using the cycler I did not need to dialyse during the day. The cycler can also be taken on an aircraft and does not count as your carry-on bag. We did this on a trip to hike in Banff National Park. In that case the fluid was delivered to our hotel.

On some trips it might not be convenient to take the cycler. This can happen if you don't need to avoid dialysis during the day. If you are travelling on a ship it is not possible to get help if the cycler breaks down. We did a short cruise on the Trent-Severn Waterway using the twin bag method. Since we went to the ship by car we took the fluid with us. When we did a three week cruise from Miami, the fluid was delivered to the ship.

Travel with PD does involve more planning. Even if you are going by car, you need to make sure that you have everything you need. For longer trips arrangements have to be made to have the fluid delivered and to make sure the hotel or resort will take delivery of the fluid. Still, for people who like to travel, whether it is a cruise or a visit to family, on PD you can do it.

by George Goodlet.

Why Protect Your Veins?

- Your arm veins provide the best access to your bloodstream should you need to have a fistula or graft created for hemodialysis

- Placing an IV or a peripherally inserted central catheter (PICC) in your arm veins, or having blood withdrawn from your arm veins, can damage the veins and make it difficult to create a fistula or graft in the future

Tips

- Wear your “Save My Veins” wristband to remind you and your healthcare provider to use a hand vein when drawing blood
- Inform friends, family and your healthcare providers about the importance of saving your arm veins

ALONG YOUR JOURNEY WITH CHRONIC KIDNEY DISEASE, THERE MAY COME A TIME WHEN YOU REQUIRE HEMODIALYSIS. YOUR ARM VEINS ARE IMPORTANT FOR THE CREATION OF A VASCULAR ACCESS FOR HEMODIALYSIS. IT IS IMPORTANT FOR YOU TO PROTECT YOUR VEINS!

For more information go to:
www.renalnetwork.on.ca/savemyveins

Cranberry Chicken

Portions: 6

Serving size: 1 chicken breast with 1/2 cup of sauce

Ingredients

1 tablespoon olive oil
1/4 cup onion
2 pounds boneless, skinless, chicken breasts
1/4 cup ketchup
1 teaspoon dry mustard
16 ounces canned whole-berry cranberry sauce
1/4 cup brown sugar
1 tablespoon apple cider vinegar

Preparation

Chop onion.

Preheat oil in a large skillet. Add onion and sauté until clear.

Add chicken and cook for 3–4 minutes on each side.

In a medium-sized bowl combine ketchup, dry mustard, cranberry sauce, packed brown sugar and vinegar. Stir until mixed and pour into skillet.

Cover and cook on medium heat for 15–20 minutes.

Renal and renal diabetic food choices

4 meat
1 fruit
1-1/2 high calorie

Dear Dr. Doctor

Dear Doctor King Faisal,

"I have chronic pain and also kidney disease. What pain medication can I safely use?"

Sincerely,
Mr. Achy Joints

Dear Mr. AJ,

Great question. The management of chronic pain or acute pain in patients with chronic kidney disease is challenging. Some of the medications damage the kidneys further. Other medications are eliminated from the body by the kidneys and, therefore, the breakdown products can accumulate and cause side effects.

My preference is to use non-medication means for controlling pain. I am a big fan of using acupuncture, ultrasound treatment, massage therapy and physiotherapy for controlling pain. If a patient needs to be started on pain medication, we need to avoid the use of non-steroidal anti-inflammatory medications (NSAIDS) that can compromise the blood flow to the kidneys and cause more scarring. Examples of NSAIDS include ibuprofen (also known as Advil or Motrin), celebrax, meloxican, Naprosyn (also known as Aleve). These medications also make our patients more prone to stomach ulcers.

The safest medication option for pain management is Tylenol when taken at the prescribed dose.

In very severe pain that does not respond to non-medication means or tylenol, you may need to use medications like Tramadol or morphine analogues to treat pain. This must be done in conjunction with a healthcare team with expertise in pain management as the metabolites of these medications can accumulate in patients with kidney disease and can cause side effects. In particular long acting morphine analogues can be very dangerous in patients with kidney disease if not dosed appropriately.

Sincerely,

King Faisal

Nikki Anderson's Story, Part 2

To review Nikki's Story, Part I, check the Fall 2014 Newsletter.

My first transplant lasted four years which got me almost through puberty. At this time I was sixteen and back on (hemo) dialysis. This is when I went to the self-care dialysis unit on Baseline Road. While there, I learned to set up my own machine and put in my own needles. Near the time I turned seventeen I received my second kidney (transplant). This kidney lasted about two and a half years. During this time I found my husband-to-be and ended up pregnant. I lost my baby at six months along, my own body poisoned it. After losing my child I lost my second kidney and was back on dialysis.

At age twenty I was back on dialysis again. During this approximately eleven year duration of dialysis I got married, I helped train nurses for the Woodstock satellite unit that was opening, moved to the Woodstock unit, and went back to school for my grade twelve. Then I tried to get a job. That was a disaster. Nobody wanted to hire someone who could only be there three to four days a week. So throughout dialysis for ten to eleven years I never had a job.

Since I lost my baby I had been thinking about having a hysterectomy so at thirty I had the surgery done, so I wouldn't lose another kidney by that means. By that Christmas, the same year I had another transplant. This kidney lasted nine years to the day.

I did a lot of things during this transplant. I had two different jobs and then went back to school for my Social Service Worker diploma. The jobs I had were third party inspector of vehicle parts and then I went to work for Cami Automotive in Ingersoll.

Now I am back on dialysis but I am at home and trying out Peritoneal Dialysis (PD) this time. PD is different and I love it, because I get to sleep through it and then I have my days to myself to do what I want for a change.

This is my story in a condensed version. I hope you enjoyed my tale.

Why we want your stories

Every kidney patient has a unique journey through their illness. We may attend the same clinics and meet the same staff but what we experience and what we feel about our experiences can be completely different. This means that every kidney patient has a different and very personal story.

London Health Sciences Centre has committed to developing Patient and Family Centred Care. This means that there will be changes to make sure that you and your family become full partners with the medical staff in deciding on your care. That may mean that changes will be made. But it also means that what is working now shouldn't be changed. The Patient and Family Advisory Council (PFAC) will be working to identify areas which should be changed and which should not be changed.

This is where your story comes in. The members of the Council have their stories and some of these have led the Council to study areas where change can be made. We need your stories to guide us further.

You may be perfectly happy with your experiences and feel your story is not worth telling but it is. What there was in the renal program that made the journey easier for you or your family is important, just as important as knowing where something didn't work as well as we would have liked.

You can tell your story to the Council, anonymously if you want, by contacting the the Council's Resource Advisor at renaladvisor@lhsc.on.ca.

By George Goodlet

WE'RE A LITTLE CONCERNED ABOUT YOUR POTASSIUM LEVELS

We're a little concerned about your potassium levels.

renal P.F.A.C.
PATIENT & FAMILY ADVISORY COUNCIL
PATIENT | FAMILY | HEALTH TEAM

Michael Hermiston: Editor

Nikki Anderson: Newsletter Design & Production