



Summer 2015

Introduction From The Editor

The Renal Patient and Family Advisory Council (PFAC) has been in existence since 2014. Following a general orientation, we held our first meeting on February 11, 2014. Since then, we have met monthly and have formed several Task groups. (See Council Activities article for a list of Task groups and their recent activates).

On June 4, 2015 a group of Patients from the council, renal staff, and administration met to discuss the future of the PFAC. We discussed our accomplishments for the time we have existed and did a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis. Several suggestions were made to attempt to recruit more diverse patients (we currently have many transplant recipients), especially patients from satellite clinics, as well as, family members.

If you, or someone you know, might be interested in joining the PFAC, please call Angela Andrews at 519-685-8500, extension 34411.

Michael Hermiston
Editor of the Kidney Kronicle



Dear Dr. Doctor,

I am a 55 year old type I diabetic, and I have just started hemodialysis in the last month. Ever since starting hemodialysis I have been having trouble controlling my blood sugars. Is there any advice that you can give me to better control my blood sugar now that I am on dialysis?



Signed: On the diabetes roller coaster!

Dear Roller Coaster:

Thank you for this question, as you are not the only person whose blood sugars have gotten out of whack when starting dialysis. Diabetes Canada has identified possible causes of hypoglycemia for anyone taking insulin or insulin secretagogues (diabetes pills that lower blood sugars).

More physical activity than usual

Not eating on time

Eating less than you should have

Taking too much medication

There are several reasons why people with renal failure often experience more hypoglycemia.

- 1. Declining kidney function:** As kidney function decreases insulin tends to hang around longer. Short acting behaves more like intermediate acting, intermediate like long, and long -- well -- really long. The reporting of more low sugars to the pre-dialysis clinic team is often an indicator to them that someone's renal function is declining. Whether you are taking insulin injections or using an insulin pump, most people find that they need less insulin to keep their blood sugars within their target range and prevent hypoglycemia.
 - 2. Diet Changes:** As kidney function declines dietary modifications are required. The carbohydrate in food needs to be balanced with insulin. The amount of carbohydrate you eat should stay the same, but the kind of foods you choose will need to change. Talk to your dialysis dietitian about low glycemic index foods that are also low in potassium and phosphorus.
(Remember: Your renal dietitian is your friend!)
 - 3. Schedule Changes:** If you dialyze in one of the units (hospital or satellite) you, unfortunately, don't have complete control over your schedule. This may impact your meal and snack regimen. If you have a long commute to/ from dialysis your meal and snacks schedule can be de-railed -- impacting your blood sugar management.
You will need to plan time for meals and snacks. Pack a lunch or stop at a restaurant along the way.
 - 4. Over-treating hypoglycemia:** Use the guidelines for treating hypoglycemia. Over-treating with more carbohydrate than needed can lead to rebound hyperglycemia and weight gain.
 - 5. Switching types of dialysis:** will also affect blood sugar control. Individuals on PD have higher insulin requirements due to the large amount of sugar in the dialysis solution. A switch to hemodialysis typically induces low blood sugars and the need to cut back on insulin doses. Conversely, if someone switches from HD to PD, their insulin requirements will increase.
- Also, consider:
- Reconnecting with your Diabetes Management Person:** This may be a specialist or your GP. Make an appointment with him/her. Let the secretary know that you have started dialysis and that your insulin requirements

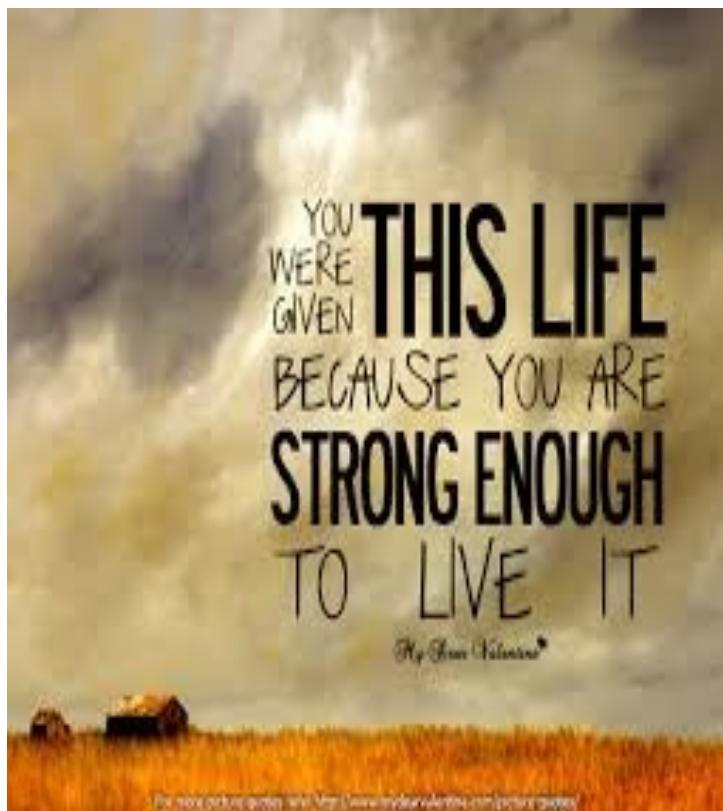
have changed. If you don't have either of these people involved in your care, the dialysis team can assist with this.

Diligently monitor your blood sugars. Share this information with your health care team (Specialists, GP, & Dialysis).

Getting a Diabetes Tune Up: If you have never seen a diabetes specialist we may refer you to one. This doesn't mean that your GP no longer helps you manage your diabetes: It's just nice to have a specialist weigh in once or twice.

Best of luck! Hopefully you can exchange your seat on the diabetes roller coaster for one in a luxury sedan!

Submitted by Ridley, Nurse Practitioner and Sheryl Forrest, Renal Dietitian



Douglas Michael

Smith's Story Part I

My name is Douglas Michael Smith, but you can call me Mike. I have been in the health care system my whole life. I was born with a rare disease called Prune Belly Syndrome. It usually attacks any of the organs in the body and also attacks development in a lot of areas, as well. I've had upwards of 20 surgeries to date for corrections of these underdeveloped areas, as well as, other complications; including misdiagnosis, medication issues, and allergic reactions to latex.



I don't remember a lot as a child but the bits and pieces I do remember are fond memories of nursing staff and the amazing care they gave me. I also remember being very curious, at a young age, about my illness and one doctor sticks in my mind the most. No matter the issue, he would always talk to me and explain in terms I could understand. He was my doctor for the first 18 years of my life at Sick Kids Hospital in Toronto. I will never forget the last words that he said me as I walked out of the hospital just after my 18th birthday. He told me "good luck" and that he never thought he would ever see me walk out of this hospital as an 18 year old man. Those words still drive me to excel in everything I put my mind to!

I had a great support system at home, as well as, in the hospitals. My

home life was like any other boy my age with the exception that there was always some sort of procedure or operation to undergo. My mother always used to say that when I was at the hospital I was sick but when I was home she would always push me to live a “normal” life. I didn't understand why, as a child, but I understand it fully now and I cannot thank my parents enough for that.

Just after my 19th birthday, I started dialysis. I'll never forget my first day walking down the hallway with my mom. We sat down and I got hooked up to hemodialysis. Instead of being in a sad state, we watched the comedy network and laughed for four hours. I am pretty sure the nurses thought we were a bit on the crazy side, but I believe that a good attitude in bad situations is a start in the right direction. I try to look at the positives in every situation. As hard as that may be it helps me in coping with the things I have had to deal with. I was on dialysis for 8 years in Niagara including the self-care program for 6 of those years. There were a few more complications in that time that were corrected with surgery.

At the age of 29 I decided to move to London. That was one of my best ideas. I attended school full time, worked, and was on dialysis. I was busy but it paid off as I finished school and started my own business. In 2002,

I got a kidney transplanted a kidney donated by my Step-Mom. After the surgery, I got the ‘flu which caused Tubular Necrosis, which basically dries out the ureters and disconnects the kidney from the bladder. That kidney lasted 3 months with tons of complications from anti-rejection drugs. The side effects were unbearable at times, but I just wanted to keep going and going. Truthfully, I don't think I was ready for a kidney at that time. I was still very immature and felt a lot of guilt for receiving a kidney from my Step-Mom. That was something I worked through for a long time, especially losing it after 3 months. It took me just before my 27th birthday to talk to my Step-Mom about it. Of course, she said it wasn't my fault, which helped me immensely to get rid of that regret in my life.

THAI SHRIMP KEBABS

Preparation: 20 minutes

Cooking time: 15-

18minutes

Allow few hours for marinating



Ingredients (Makes 8 skewers)

1 cup red peppers, cubed

2 small onions, quartered

2 cups cauliflower, cut in florets

1/2 cup fresh lime juice

1/2 cup white wine

1 tablespoon red or green Thai curry paste

1/2 cup vegetable oil

**1/3 cup fresh basil or
1 1/2 lbs shelled raw shrimp
(suggested size 31-40)**

Note: This is a great recipe for your summer party. Recipe can easily be halved.

PREPARATION

Cut red peppers and onions.

Put cauliflower in boiling water for 2 minutes, drain and set aside.

In a large bowl, blend the lime juice, wine, curry paste, oil and herbs together with a whisk. Toss in shrimp and all vegetables and marinate in the fridge for a minimum of 1 hour, up to 12 hours.

Place the shrimp and vegetables on skewers, alternating them attractively.

Grill on BBQ on medium heat for 15 to 18 minutes or broil on a baking sheet in your oven for 15 minutes, turning them once. Serve with basmati rice.

Count 1 serving (1/8 of recipe: 1 skewer) in your meal plan as:

2 Meat & Alternatives

1 Fruit & Vegetable

Council Activities

Momentum of Council activities remained strong with a continuation of the work of our Task Groups as follows:

- The Transportation Task Group is proceeding to engage the service

providers to explore ways to improve scheduling and reservation procedures;

- The Feedback Task Group has completed the first of planned visits to dialysis units in the satellite offices. Our visit with patients, administration, and nursing staff at the Woodstock General Hospital opened the process of sharing information and measures to optimize patient and care-giver experience;
- With the assistance of a Staff Librarian at LHSC, the Resource Task Group is entering the design and content phase for the patient and caregiver information Kiosks. These will be located in the waiting areas of the care centres, where everyone will have access to the material.

Janice McCallum, Director, Renal Program, briefed Council on the recent Updating of the Ontario Renal Plan II. The Ontario Renal Network (ORN) consolidates the planning and over-sight of Renal Program delivery across Ontario. Members of the medical and administrative staff at LHSC are leaders in this initiative which will function with a strong emphasis on patient and care-giver experience.

In early June, Council members and Renal Program staff met at Victoria Hospital for a planning retreat. The purpose of the retreat centered on the effectiveness and future direction of the Renal Patient and Family Advisory Council. This exercise will guide Coun-

cil activities into the future with a view of aligning with the goals and objectives of the Ontario Renal Network and LHSC.

Submitted by Fred McInnis



Big congratulations to the Home Hemodialysis Team for reaching a milestone of 60 patients dialyzing at home!!

We need to applaud the patients who make the commitment to choose Home Hemodialysis and the team who supports these patients!

Way to go!!



Ontario Renal Network

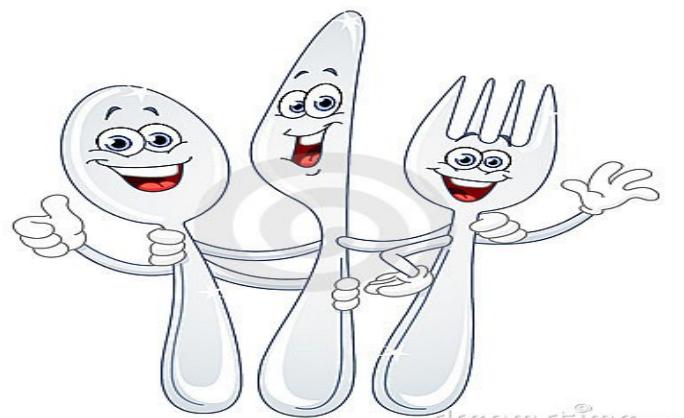
Patients, caregivers, living kidney donors and transplant recipients, we want to hear from you about Peer Support!

Whether or not you have used Peer Support, the Kidney Foundation of Canada and the Ontario Renal Network would like your input. A paper and online survey will be made available at your hospital in the coming weeks. Your participation will help us improve

Peer Support services for all those affected by kidney disease in the province of Ontario. Please stay tuned for more information and we look forward to hearing from you!

I just went on a strict renal diet. There are only three things I can put in my mouth>

**A FORK,
A KNIFE,
and A SPOON.**



Michael Hermiston: Editor

Nikki Anderson: Newsletter Design & Production