

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday, November 4, 2014
5:00pm to 7:00pm
Kidney Foundation Office, Westmount Mall**

In Attendance: Patient & Family Members: George Goodlet (Chair), Fred McInnis (Vice Chair), Michael Hermiston, Dennis Hokansson, , Paul Dixon, Nikki Anderson, Bonnie Field, Bill Landry, Don Smith

Regrets/Absent: Les Miles, Joan McArdle, Brian Carroll, Nancy Wilder, Dr. Rehman, Jarrin Slattery, Deb Bezaire

Staff/Physician Members: Janice McCallum (Advisory Program Sponsor), Angela Andrews (Advisory Resource), Carolyn Ingram

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	Welcome extended; quorum achieved. Approval of October 6, 2014 meeting minutes	
2.1	Publicity Committee Report	<ul style="list-style-type: none"> -The newsletter will be published on Nov 17 -Mike and Nikki distributed a draft copy - Recipes need to be reviewed by a dietician, so might take a little longer -It was decided to keep the paper colour in white so the pictures show up well -the suggestion was made to add more white space and photos -it was decided to keep the individual's name that submitted the article with the article, as opposed to a contributors list at the end 	<ul style="list-style-type: none"> -Angela will get a folder of recipes from the renal dietician for use in this and future copies of the newsletter -When final draft completed Angela will print and distribute -Nikki will rearrange
2.2	Letter to Patients	-the letter to patients/families/staff is ready to go	-Angela will apply George's signature to the letter and then send it out

3.1	Patient Feedback Task Group Report	<p>-the results of the Home Hemodialysis survey were mostly positive, patients/families generally happy with the home program, a number of responses indicated that there were high levels of anxiety surrounding a patient being told they would be required to start some form of renal replacement therapy, as well as around dialysis access insertion (CVC or fistula)</p> <p>-it was decided to make a recommendation to program admin. to add the Kidney Foundation Support Line phone number to the back of hemodialysis unit appointment cards so that patients can easily find the number and get some support if needed</p>	<p>-George will send a formal recommendation to Janice</p>
3.2	Bloodwork Results Sharing Task Group	<p>-no new information to report on at this time</p>	
3.3	PEP project Report	<p>-PEP intends to interview 10 patients who left the program, 5 because of peritonitis and 5 because of inability to cope</p> <p>-7 interviews have been arranged so far that will be conducted with each individual to determine why they left the program and how they felt they could be better supported</p> <p>-the open ended interviews will be conducted by 1 individual to maintain consistency and will be recorded</p>	
4.1	Staff ID Initiative	<p>-a decision was made by the Renal Admin. based on the recommendation by the RPFAC to provide clear and easily distinguishable name tags to all staff in the Renal Program</p> <p>-program coordinators have been spreading the word that this initiative was recommended by the PFAC and will follow up to make sure staff are wearing them</p> <p>-feedback has been positive from staff</p> <p>-physician group is deciding if they feel the name tags are necessary as most of them have their name on their lab coats</p>	

4.1.1	ORN Patient and Family Advisory Summit	<p>-Mike, Bonnie and George and Janice will be attending the ORN PFA Summit on Monday Nov 10</p> <p>-Janice and George will be giving a 5 minute bullet presentation on background experiences and model of care that our council is using (Institute for Patient and Family Centred Care), as well as successes and challenges that the council has faced</p>	<p>-George and Janice will report on the Summit at the next meeting</p>
4.2	Patient Transportation Issues	<p>-over 39% of patients in the program use some form of transportation to get to and from appointments, and of those, 13% use Paratransit and 10% use Voyager</p> <p>-Janice shared that the 2015 ORN plan includes working on transportation issues for patients, and any info gathered by our group could then be fed into the ORN investigations as well</p> <p>-the 7 Native Reserves that LHSC serves have 7 different transportation programs</p> <p>-Fred suggested that the council create a patient transportation task group, Angela, Nikki and Don agreed to join</p> <p>-Carolyn suggested the task group meet with social workers in the program to get their take on the issues, and to hear what patients are telling them</p> <p>-Mike reminded the group that in the Nov. issue of the newsletter, there is a section asking for patients to contact Angela if they have any transportation problems</p> <p>-the council is concerned about not only the cost of transportation, but the quality as well</p> <p>-“Can’t is not in the council’s vocabulary” (for you George!)</p>	<p>-Angela will arrange a meeting with the task group and social workers</p>
5.1	Goals and Future Directions	<p>-the group agreed that we will not purchase pens with our unlogo at this time, they are really no longer needed for any special event, we will save the money and possibly use it later</p> <p>-Don inquired about getting some more official looking name tags for the council</p> <p>-the possibility of getting a golf shirt with our unlogo and the LHSC logo was discussed</p>	<p>-Paul will look into pricing for name tags</p> <p>-Don will talk to a friend about getting a price for golf shirts</p> <p>-Angela will get approval of funds from Deb for name tags and shirts</p>

		<p>-the group talked about promotion, and possibly having a poster and/or brochure included in the material given to new CKD patients , including the “Living with Kidney Disease” Binder</p> <p>-for inquires/questions/comments coming from patients or families, it was recommended that it will be forwarded on to George and Fred, who will bring the information to the council if required</p> <p>-patients can e-mail or write a letter to the council, or the best option could be the specific individual could attend a PFAC meeting</p> <p>-Bill suggested that at the Westmount Mall on the parking levels there is a sign that says to call KCC if a wheel chair is required, however there is no phone to actually call from, it was suggested to make a recommendation to Renal Admin. to have a phone or intercom installed</p> <p>-the need for an Aboriginal PFAC member was discussed, we have a large population of Aboriginal patients and would benefit from having a voice on our council</p> <p>-Carolyn mentioned the Southwest Ontario Aboriginal Health Access Centre</p> <p>-Fred has a contact who may be able to put us in contact or to help us advertise</p> <p>-we also would like to get more satellite unit patient/family involvement</p> <p>-the Kidney Foundation Patient Christmas Party is on November 30, it was suggested that someone from the Council speak at the dinner to promote the council as well</p>	<p>-Angela will follow-up with NCM’s and social workers</p> <p>-George will make an official recommendation to Janice</p> <p>-Angela will ask Janice to enquire with Native Interest Group if there is anyone willing to join</p> <p>-Carolyn will contact</p>
5.2	New Hemodialysis Treatment Chairs Trial	-coordinators at UH/KCC/VH dialysis units will be trialing some new treatment chairs, and some patient input has been requested	

5.3	Holiday Message from PFAC	<p>-Bill and Paul agreed to meet with the coordinators to give their opinion on what criteria they should look for in choosing a dialysis chair</p> <p>-it was decided that the PFAC will send out a holiday card to in-centre, satellite, PD and Home HD patients to wish patients "Season's Greetings" and to generate some publicity</p>	<p>-Angela will arrange a meeting</p> <p>-Angela will arrange the cards and deliver them to each in-centre unit for the clerks to distribute</p> <p>-Angela will contact PD and Home HD clerks to arrange for cards to be mailed out</p>
5.4	Corporate Advisor Orientation	<p>-the date for the Advisor Orientation is Tuesday January 20 at 5:30pm</p> <p>-new advisors are strongly recommended to attend, and past advisors are also invited, as well as staff advisors</p> <p>-Don volunteered to participate on the planning committee</p> <p>-there is also a 6 session Story Telling Workshop for Advisors planned for February 2015, all advisors who would like to learn more about sharing their personal health story are invited to attend</p>	<p>-Angela will send out information</p> <p>-Fred will participate as a representative for the Renal PFAC</p> <p>-Angela will send out information</p>
6.0	Story Sharing	Nikki shared her 30 year Journey with Kidney Failure	
7.1	Meeting Adjournment	<p>-the next meeting will take place on Tuesday December 9, 2014 In the Kidney Foundation Offices at Westmount Mall</p>	