

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday November 10, 2015
5:00pm to 7:00pm
Kidney Foundation Office**

In Attendance: George Goodlet (Chair), Angela Andrews, Deb Bezaire, Janice McCallum, Bonnie Field, Philip Varughese, Nancy Wilder, Dr. Rehman, Robert Barnicoat, Carolyn Ingram, Nikki Anderson, Mike Smith, Dennis Hokansson, Don Smith, Deb Deaupre

Regrets/Absent: Dr. McIntyre, Brian Carroll, Michael Hermiston, Jarrin Penny, Paul Dixon, Fred McInnis (Vice Chair)

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	-September 8 minutes approval and Oct 6 notes approval -Welcome guest Sandee Matthews from Baxter -welcome to new advisor Deb Beaupre	
2.1	Baxter Patient Education Tool	-Sandee Matthews and Cecelia Li from Baxter Canada presented “Dialysis Snap Shot” a patient education tool -the tool educates and guides patients and families through the dialysis treatment decision process and can be accessed by anyone for free over the internet	www.kidneycampus.ca
3.1	Patient Resource Task Group	-the group has finalized the proposal and has submitted to Janice -awaiting estimates from outside company regarding the creation of a display rack which will hold brochures, a suggestion box, business cards, etc.	
3.2	Patient Feedback Task Group Report Satellite Visits	-Hanover satellite visit was completed on Oct. 28. George, Don and Angela attended -heard a lot about transportation and lack of availability or funding for transportation in their own community -patients felt it was not their choice that certain health care options were not available in their own community, so they should be compensated for their travel -Chatham visit planned for December 1 st , George, Angela, Fred, Bob and Don will attend	-satellite visit report attached

<p>3.3</p>	<p>Patient Transportation Task Group</p>	<p>-George mentioned that one of the patients did not give feedback, even though she was given the opportunity due to a possible fear of reprisal, Dr Rehman suggestion having patients fill out confidential feedback forms -George mentioned that in a very small dialysis unit some patients may fear giving honest feedback because even though it might be anonymous, the patient may still be more likely to be identified -the ORN is looking at provincial wide validated tools for collecting feedback from patients and families -Patient Experience is looking at “Just In Time” surveys, and different vendors for creating a patient feedback form -rather than the Renal program creating a feedback tool, we want a validated, tested tool, so waiting to see if LHSC or the ORN comes up with one first -Janice suggested that once all of the satellite visits are completed that the findings are summarized into common themes so we can get an idea of the big picture and recommendations for improvement</p> <p>-the survey is near completion and once done Angela will take it out to the dialysis units -Young will talk to all of the social workers and get lists of paratransit users in the 3 dialysis units -the plan is to send a letter to the managers of the service outlining our issues -George suggested that the transport task group could also look at the costs that patients are incurring for travel to dialysis when they live out of town, and the waiting list time for satellite units</p>	
<p>3.4</p>	<p>Newsletter Task Group</p>	<p>-next issue is planned for mid November, please make sure that articles are in to Mike H. and Nikki</p>	
<p>3.6</p>	<p>Patient Experience Coordinating Committee</p>	<p>-working groups still in process</p>	
<p>3.7</p>	<p>Water consumption for home hemodialysis machines</p>	<p>-George has been in contact with Sal Treesh (home dialysis biomedical technician) regarding water consumption for home dialysis machine -the water usage is very high, George is planning on following up with Sal to get a little more information</p>	
<p>4.0 4.1</p>	<p>Open Discussion Work Plan for 2015/16 Council Year</p>	<p>-the PFAC executive met to layout the work plan for the council for the year ahead, continuing on from the Planning retreat in June -the suggestion has been made to combine the Newsletter and the publicity task groups together, and call it the “Communications task group”, the members of the communication task group would be responsible for:</p> <ul style="list-style-type: none"> • the newsletter 	<p>-see Work Plan attachment</p>

		<ul style="list-style-type: none"> • advertising the council • PFAC web page updates <p>-Fred, Nikki, Mike H., Paul and Don will be on this task group</p> <p>-it was also suggested to create the "Recruitment & Orientation Task Group", this group will be responsible for:</p> <ul style="list-style-type: none"> • recruiting new PFAC members, and Patient and Family Advisors (associate members), • interviewing new recruits • the creation of renal pfac specific orientation that could be held a number of times yearly when new members are on boarded • membership on the LHSC wide PFAC Orientation planning committee • recruiting for and membership on the LHSC wide Story Telling workshop planning committee <p>-Nikki, Don, Fred and Angela will be on this task group, and possibly Betty Clinton, one of our newest members when she is ready to join the council</p> <p>-each task group will also be asked to complete a work plan for the coming year to assign tasks and pinpoint responsibility and set a time line</p>	
4.2	Terms of Reference amendments	-terms of reference amendments on pages 6, 7 and 9 were completed, and passed by council	-see attachment of Final Copy of Terms of Reference
4.3	Renal PFAC Executive	-Paul, Don, Nikki, Bob, Mike all expressed interest in joining the PFAC Executive Team -we will do an e-mail vote for each of the candidates -the next Executive team meeting is December 2	
4.4	LHSC Advisor Orientation	-the LHSC wide Advisor Orientation will take place on Saturday January 30 th from 09:30am to 3:00pm at Victoria Hospital -the planning committee is looking for volunteers (who have been to the event before) for the day of the event to give people directions and help with set up and clean up, please let Angela know if you are interested in volunteering that day	
4.5	Kidney Foundation volunteers	-Riz from the Kidney Foundation is looking for some volunteers to help with the KF Patient Christmas dinner	

<p>4.6</p>	<p>Joint ORN/Kidney Foundation Peer Support Study</p>	<p>-the ORN and the Kidney Foundation are working on a study of the Peer Support Program that the KF offers -the survey will go out to all renal patients in the province -please go to the link and complete before the end of December</p>	<p>www.cco.fluidsurveys.com/s/peer/</p>
<p>4.7</p>	<p>Bios and Photos</p>	<p>-Angela will set up a photographer to come to the January meeting for a group PFAC photo -if you are not present for the meeting in January individual head shots for the website can be arranged for the same time as going to customer support to have your photo taken for your hospital ID badge, arrange this with Angela -also, for the newer members on the list we need to collect a bio from you for the Renal PFAC webpage, please visit the link to see what other members have written to get an idea of what we are looking for</p>	<p>www.lhsc.on.ca/Patients_Families_Visitors/Renal/AdvisoryCouncil/index.htm</p>
<p>4.8</p>	<p>Privacy rules surrounding sharing when a patient passes away</p>	<p>-Deb contacted the privacy office about confidentiality rules when a patient passes away -as long as the person asking can mention the deceased by name, it is legal for the hospital employee to share that the patient has passed away or that the patient is in the hospital, but the asker must know the person well enough to ask for them by their name -if the patient has requested to be anonymous no information can be shared -Deb will send this information out to all staff members within the renal program</p>	
<p>5.0</p>	<p>Meeting Adjournment</p>	<p><u>Next Meeting:</u> Tuesday December 8 , 2015 at 5:00pm at the Kidney Foundation Office</p> <p>Don't forget to fill out your survey on the Peer Support Program www.cco.fluidsurveys.com/s/peer/</p>	