

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

In Attendance: Fred McInnis (Vice Chair), Michael Hermiston, Bonnie Field, Brian Carroll, Mike McCracken, Don Smith, Angela Andrews, Philip Varughese, Deb Bezaire, Janice McCallum, Dr. McIntrye, Jarrin Slattery, Robert Barnicoat, Nancy Wilder

Regrets/Absent: Nikki Anderson, Paul Dixon, Bill Landry, George Goodlet, Dr Rehman, Dennis Hokansson, Carolyn Ingram

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	<ul style="list-style-type: none"> -Quorum Achieved -it was discussed whether or not to include the amendment offered by Rachelle Wood around her comments on the Facebook page -it was agreed that we would include the amendment, and send the new version out with the March meeting minutes -an update was also included on the “KCC TV situation”, some work has been completed, but still not showing the full channel selection 	-Janice will follow up
2.1	Patient Resource Task Group	<ul style="list-style-type: none"> -the group has decided that the creation of a “patient information kiosk” would be helpful to patients, and plans to propose this to Janice -the kiosk would include information relevant to renal patients needs, and would consolidate all educational material etc. in one spot (for example social worker contacts, patient stories, and education info) 	

2.2	Patient Feedback Task Group Report	<p>-we also plan to include an I-Pad tablet or some type of computer for access to the Renal Patient Web and on-line educational materials</p> <p>-our next meeting is planned for March 24, where a LHSC library services representative will attend to get us started with some ideas on planning the kiosk</p> <p>-this task group has proposed to Janice that PFAC visit the satellite hemodialysis units to hold an open forum, and get a sense of the needs of more rural kidney patients</p> <p>-the plan is to visit Woodstock Satellite Unit first around the end of April as a trial run to see what kind of response we get from patients, an invitation will be extended to PD, HH and CKD patients as well</p> <p>-information gathered from patients could include what issues do they experience as a rural kidney patient, are there transportation problems</p>	
2.3	Patient Transportation Task Group	<p>-Anne Brinkman from the KF and Selena Buma, a Renal Social Worker have joined the task group</p> <p>-the plan is to invite paratransit representatives to sit down with the group to discuss our issues (listed below)</p> <ul style="list-style-type: none"> • 3 day call in advance to book ride • Prioritization of dialysis patients, who require this service to attend a life saving treatment • Request the dedication of a specific bus for dialysis patients <p>-we plan to invite a dialysis patient and staff member from each site to attend this meeting</p>	

		<ul style="list-style-type: none"> -we also discussed going to London City Council with this issue -we have asked the Renal SW to track paratransit usage over the month of March to have concrete data to show paratransit 	
2.4	Newsletter Task Group	<ul style="list-style-type: none"> - the next issue of the newsletter is set to come out early April 	-please submit all content to Mike H. before March 20th
2.5	PEP Project	<ul style="list-style-type: none"> -the project team has 2 task groups looking at the PD Clinic Model and the PD Primary Patient Care Model -the plans from these teams are being implemented this week, which are adapting how the clinic appointments are scheduled to decrease wait times, and to implement primary care groupings instead of primary nurse, so the group can see their patients 	
2.6	Patient Experience Coordinating Committee	<ul style="list-style-type: none"> -this committee is currently working on how LHSC is integrating patient and family centred care into their clinical daily activities throughout all programs and areas in the hospital -there is representation from all areas and disciplines across LHSC -this committee also provides a link between the PFAC's from every program at LHSC 	
3.0	Recap/ Parking Lot Document	<ul style="list-style-type: none"> -we reviewed the parking lot document and the follow ups -Anne Brinkman will attend April 2015 meeting to discuss KF and Peer Support -we will ask George to update us in April on his meeting the hospital lawyer to discuss municipal water grants 	-see attached document

		-we will reestablish the Publicity Task Team and add to April Agenda	
4.1	Patient Story Telling	-Deb stressed the importance of patient story telling, and the workshops offered for advisors -currently we only have one Advisor Storyteller, and need more to share stories -there will be periodic story telling workshops that we encourage as many as possible to attend	
4.2	Research	-Dr McIntyre shared some of the Renal related research that he has done in the UK, and shared plans for a province wide study to look at the heart and brain protective effects of cooling the dialysate during hemodialysis -he asked for several patients to join the steering committee for this research project	-Mike M. and Brian Carroll have volunteered for this steering committee
4.3	Vital Behaviours/ Awards World Kidney Day/ Patient Experience Week/ Facebook Page	-Janice requested several more advisor volunteers to attend the Vital Behaviours sessions this week -Janice mentioned the “20 Faces of Change” Award received by the LHSC Renal Patient Web Creation Team -World Kidney Day is March 12, Don will be representing the Council at the display along with the KF and Nurse Case Managers from KCC -Patient Experience Week is April 27 to May 1, stay tuned for more info coming from Patient Experience Dept -Janice talked with the Director of Communications about a Facebook page associated with the PFAC, there are very strict guidelines and protocols that any page associated with LHSC must meet those	-see link: http://www.20faces.changeofoundation.ca/the-winners/

		<p>protocols</p> <ul style="list-style-type: none">-some things to think about are the lack of secureness of the info, there is no way to secure that info on the internet, also the “owner of the page” would be at risk if anything unforeseen were to happen as a result of something that was posted on Facebook- some alternatives were suggested to further reach our renal population, including a mass mailing of information (our intro letter, the newsletter, etc) to all patients within the renal program, including a link where patients can do a “Survey Monkey”, and add in their e-mail address so we can further contact them and create an e-mail distribution-Neil Johnson will extend financial support for this-it was suggested that a register be added to the Renal Patient Web, where patients could register their e-mail address so we could create an e-mail distribution-Corporate Communications could do “internet information blasts” on the LHSC Facebook and Twitter pages, where the PFAC would work with corporate to write the content, but LHSC would own it to ensure all protocols were followed-Janice offered to meet with the Publicity Committee to further discuss this-Mike M. suggested that Twitter and Facebook won’t necessarily reach all of the renal patient population, as not everyone is connected or interested in the internet	
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<p>4.4/4.5</p>	<p>Patient Intervention/ Satellite and Rural Patients</p>	<p>-Fred has referred an issue of a specific rural patient regarding home hemodialysis to Janice -Janice has communicated with the patient and is awaiting a reply -the patient was advised that Council will try to ascertain the impact of home hemodialysis on well and septic systems in rural areas and will support alternative units if and when they become available -Janice noted that several of the units identified by the patient are being tested at LHSC and will follow up to ascertain if and when the units may become available for rural patients. The patient was advised that Council does not have a delegation of authority and can only make recommendations regarding patient care</p> <p>-Janice mentioned the Renal Program will soon be looking at the purchase of new home hemodialysis machines, and would like to have some patient representation on the selection group</p>	<p>-both Philip and Nancy volunteered to be on this committee</p>
<p>4.6</p>	<p>Conferences/Workshops Council Activities</p>	<p>-Fred reminded everyone to please inform Angela of the activities each member is participating in so it can be recorded and used to track the impact that the council is having</p>	
<p>4.7</p>	<p>Round Table Discussion</p>	<p>-the question was asked if there has been any interest from patients for evening clinics or weekend clinics – Deb, as Program Manager says this is a process that can be looked into -there was mention of how many patients who are still working, it was estimated approx. half of clinic patients</p>	

6.1	Meeting Adjournment	<u>Next Meeting</u> : Tuesday April 14, 2015 <u>Stories if Illness and Health</u> : March 19, 6:30-8:30pm Wolf Performance Hall at the London Public Library main branch	