

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

In Attendance: George Goodlet (Chair), Fred McInnis (Vice Chair), Michael Hermiston, Dennis Hokansson, Bonnie Field, Brian Carroll, Don Smith, Angela Andrews, Carolyn Ingram, Philip Varughese, Deb Bezaire, Janice McCallum, Dr. McIntrye, Jarrin Slattery, Lisa Hawthornthwaite (Pt Experience), Rochelle Wood (Pt Experience), Bob Barnicoat, Dr. Rehman, Nancy Wilder

Regrets/Absent: Nikki Anderson, Paul Dixon, Mike McCracken, Brian Carroll, Bill Landry

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	Quorum achieved. Approval of January 13, 2015 mtg minutes.	
1.2	Introductions	-round table introductions were made, since there are a number of new council members	
2.1	Guest Speaker	<p>Lisa Hawthornthwaite and Rochelle Wood joined us from the Patient Experience Office to talk about PFCC, patient engagement at LHSC, the Drive framework, the Beryl institute, and levels of decision making with regards to PFAC recommendations</p> <p>-there was discussion around the levels of decision making framework, and suggestion that each council does not report directly to the Patient Experience Coordinating Committee, rather to the leader of each program, and then further up the leadership chain for decisions that affect all of LHSC</p> <p>-George suggested to have a subgroup that consists of advisors from all PFAC's across LHSC to discuss what is going on at each council, or at least a sharing of minutes between PFAC's</p>	<p>-see attached documents</p> <p>Beryl Institute: www.theberylinstitute.org</p> <p>Institute for Patient and Family Centred Care: www.ipfcc.org</p>

		<p>-there has been planning around having more regular Advisor /Provider workshops to continue contact with other PFAC's and promote learning about PFCC for advisors and care providers</p> <p>-it was identified that a more clear definition of the Patient Experience Coordinating committee is required and what its role is</p> <p>-Lisa requested to be kept informed on the transportation task group work, and offered assistance when needed</p>	
3.1	Patient Feedback Task Group Report	<p>-task groups have not met since last PFAC meeting, meetings planned for this month</p>	<p>-Angela will send out a "Doodle" request when trying to book meetings with task groups to better assess availability of individuals in the group</p>
3.2	Patient Transportation Task Group		
3.4	Newsletter Task Group		
4.0	Recap	<p>-Angela has been in contact with coordinator Gail Barbour, who has had 4 TV's at KCC, 1 at UH and 1 at VH outfitted with devices so that education material can be displayed, with thanks to the Transplant program, which the PFAC is free to post information</p> <p>-the Patient Resource Task Group will be responsible for deciding what info will be displayed from the PFAC</p> <p>-Janice replied to George's recommendation previously</p> <p>-George has been in contact with Anne Brinkman, who would like to come in March/April to talk about what the Kidney Foundation does for renal patients</p> <p>-Angela will also inform Anne of the request for more Peer Support posters</p>	<p>-Angela will arrange to have info posted when it comes available on an on-going basis</p> <p>-Angela will invite Anne for our April 14th meeting</p>
4.1	Previous Recommendations:		
4.1.2	Waiting room TV's for advertising		
4.1.3	Peer Support number on patient appointment cards		

5.1	Open Discussion		
5.1.2	Facebook Page	<p>-Don suggested that we create a Facebook page to advertise the Renal PFAC since so many people are using social media now, and since we have a large satellite and home dialysis patient population, it will make it easier to reach the rural patients</p> <p>-Mike suggested that since it was very difficult to find the Renal PFAC page on the patient website, and thought that a Facebook page, with a link to the PFAC page would be helpful</p> <p>-Don indicated he would maintain the page</p> <p>- Rachele Wood (previously from Corporate Communications) explained that individual dept or service Facebook pages are not permitted and that LHSC has an official page run directly by corporate communications). All LHSC FB content is approved by corporate communications since the information displayed on the page reflects back on LHSC and there is a need for providing consistent and correct information.</p> <p>-the suggestion was made to create a page not directly using the LHSC name or logo, or Renal PFAC logo, just calling it a Renal Patient Support Group and not seek corporate approval</p> <p>-Rachele suggested that a proposal is created that indicates what we would like on the page, what topics, what information and pitch this to corporate before putting too much time and work into it</p> <p>-Lisa suggested a benchmarking scan to see what other hospitals and programs are doing in the province</p> <p>-Fred offered to put information on IPFCC Advisor Network to see what other institutions and advisors are doing</p> <p>-Dr. McIntyre talked about his Arts based Research projects</p>	<p>-Rachele will provide contact names from Corporate Communications</p> <p>-Angela will follow up with Lisa on benchmarking</p>

5.1.3	Dr. McIntyre/Research	<p>where renal pts are given a camera to take photos of anything that relates to their life, and the art dept. will then create art from these pictures to represent how a renal patient may feel</p> <ul style="list-style-type: none"> -he also talked about his Patient Experience research regarding the physical/visual dialysis environment, and a possible artistic redesign of a dialysis machine taking in to account patient anxiety related to seeing the machine -he brought a draft survey for the council to review 	<ul style="list-style-type: none"> -see attachment -please review the draft survey and reply to Angela with any comments by Tuesday Feb 24 so it can be forwarded on to Dr. McIntyre
5.1.4	World Kidney Day	<ul style="list-style-type: none"> -Janice mentioned that Thursday March 12 is “World Kidney Day” -the council decided to participate strictly at KCC by participating in a display at the mall on March 12 along with the Kidney Foundation and KCC volunteers -Don has volunteered to man the display - the council will plan to participate at all sites for World Kidney Day in 2016 since there isn’t quite enough time to get involved at all sites this year -Janice also shared that the ORN is launching new educational materials on World Kidney Day 	<ul style="list-style-type: none"> -Angela will ask Paul if he would like to participate as well -Janice will contact corporate comm. to promote the day
5.1.5	Visiting Satellite Units	<ul style="list-style-type: none"> -George suggested that we should be planning to go out to the satellites to promote the council and to hear concerns from patients in the rural areas -we could visit patients in the dialysis units, as well as provide an open forum space for CKD, and home dialysis patients to come and talk with us as well 	<ul style="list-style-type: none"> -the Patient Feedback Group will follow up on this
5.1.6	KCC Patient TV’s	<ul style="list-style-type: none"> -the purchase order for the device required to get digital channels at KCC has been completed, now just waiting for Roger’s cable to install it -Janice updated that the satellite patient concerns shared at the 	

5.1.7	Patient Concerns	last meeting were passed on to the Director of the specific unit to be looked at	-Angela will follow up
5.1.8	Out of Date Website Content	-it was commented that info on Patient Website, especially in the "Upcoming Events" section are out of date -there is also concern about the difficulty in finding the PFAC webpage on the website	-Angela will add this to the minutes
5.1.9	Parking Lot and Advisor Activities	-Bonnie suggested that the minutes should include a "Parking Lot" Page, where previously discussed activities, that haven't been started or fully completed yet can be reported on, as well as an Advisor Activities List to keep track of what each Advisor is involved in month to month -Deb suggested that a Patient Experience Coordinating Committee Report be included on the meeting agenda also	-Please send Angela an e-mail with the activities that you have been involved in, and the dates to add to the Activities List
6.1	Meeting Adjournment	Next Meeting: Tuesday March 10, 2015 Story Telling Workshop: Tues Feb 17 or Thurs Feb 19 at 5:30 to 7:30pm and Tuesday Feb 24 or Thursday Feb 26 at 5:30 to 7:30pm (choose total of 2 sessions)	-Please RSVP to Angela by Thursday Feb 12 th if attending