

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday, December 9, 2014
5:00pm to 7:00pm
Kidney Foundation Office, Westmount Mall**

In Attendance: George Goodlet (Chair), Fred McInnis (Vice Chair), Michael Hermiston, Dennis Hokansson, , Paul Dixon, Bonnie Field, Brian Carroll, Don Smith, Nancy Wilder, Angela Andrews, Carolyn Ingram, Dr. McIntyre

Regrets/Absent: Dr. Rehman, Jarrin Slattery, Deb Bezaire, Janice McCallum, Nikki Anderson, Bill Landry

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	Welcome extended; quorum achieved. Approval of November 4, 2014 meeting minutes	
2.1	Publicity Committee Report	-Fred attended the Kidney Foundation Christmas dinner on November 30 and said a few words on behalf of the Council, as well as handing out some of the flyers and letters -a number of Patients spoke to Fred about issues they are experiencing all over the program	
2.1.1	Newsletter	-Angela has sent out a newsletter, as well as a Holiday Greeting and Council letter to all PD and Home hemo patients via mail, with an insert asking readers to sign up for the newsletter by e-mail	
2.1.2	Letter to Patients/Family/Staff	-copies of all 3 pieces have been handed to all in-centre dialysis patients -a newsletter and council letter has been sent to all staff via e-mail, as well as e-mailed to all satellite units to be printed and distributed at each location	

		<p>-there was much discussion on CKD patients and how to get both the Council letter and newsletter out to over 1200 patients</p> <p>-the letter has been printed in poster size and will be hung on the wall at CKD, and transplant clinic</p> <p>-it was decided that we ask Deb for approval to hang display boxes on the wall outside of the CKD and transplant clinics, which will have both the letter and newsletter available for CKD patients to take if they want one</p> <p>-Angela will print 100 copies for each site, and have the clerks replenish the boxes when they deplete</p> <p>-Angela will monitor the number taken, so that if required we can have the next issue of the newsletter mass printed via the Data group in order to save money on printing and paper</p> <p>-eventually when the PFAC Network is available on-line for all patients the newsletter can be posted there as well</p> <p>-Fred feels strongly that the Council letter should be mailed out to each CKD patient, to make positive contact at least once with every patient</p> <p>-we will also include a spot on the next newsletter to contact Angela with any suggestions and also to be added to a subscriber list</p>	<p>-Angela will ask for approval from Deb for money for printing, and display boxes</p> <p>-Angela will ask clerks and coordinators for them to follow this</p>
3.1	Patient Feedback Task Group Report	-the task group is interested in getting more feedback from satellite units	
3.2	Bloodwork Results Sharing Task Group	-Carolyn is using the bloodwork form in her own practice with hemodialysis patients	
3.3	PEP project Report	-patient interviews are being completed now	
3.4	Patient Transportation Task Group	-Nikki, Don and Angela will meet with social workers on December 15	

4.1	Recap	<p>-a new section has been added to meeting agendas called "Recap" as it was identified at the ORN Summit that a lot of groups had great ideas, but things were not always followed up</p> <p>-to ensure that our group is following up, we will discuss previous items and what follow up has been done</p> <p>-there was discussion about making a recommendation to Janice for a phone to be available to call KCC from the parking and main levels at Westmount Mall if help is needed to get to dialysis, the group is unsure exactly what the issue is, as there are phones (payphones) available on the parking levels, but not at the main doors</p>	<p>-Bonnie has created a Recap document, and will maintain the list so that we continue to follow up with item</p> <p>-document is attached</p> <p>-Angela will follow up with Jarrin and Bill and report back at the next meeting</p>
4.2	Review of Previous Meetings	<p>-George has a meeting with hospital lawyer to discuss the municipal water grants and home hemodialysis patients</p> <p>-It was suggested that in order to better support patients and families when they first learn of their need for dialysis to start soon, that the program can add the Kidney Foundation Peer Support number to the back of appointment cards handed out by the dialysis units incase the patient feels they need more support (Nov 2014)</p> <p>-Carolyn has been working on process of being notified asap when a new in patient starts dialysis</p> <p>-Carolyn's current process is forming relationships with all Nephro fellows to have them notify her</p> <p>-there is no formal process at this time however Carolyn also attends twice weekly rounds at UH, weekly formal rounds at VH and also 4 times weekly bullet rounds at VH</p> <p>-Carolyn will keep stats around how many new in-patients start hemodialysis without her being notified (July 2014)</p>	<p>-George has submitted a letter of recommendation to Janice</p> <p>-George has talked with Anne Brinkman from the Kidney Foundation about this</p>

		<ul style="list-style-type: none"> -bulletin boards are available at KCC/UH and VH (March 2014) -the patient feedback task group had previously talked about having Anne Brinkman do some peer support training for those on the council who may do some patient on patient interviews, but no plans for interviews have been made yet (March 2014) -George has also talked with Anne about the council having more Kidney Foundation Peer Support members, and having them be put in contact with people in London or this area -PD Heparin supply, it has been determined that this is no longer an issue for the council, however it was suggested that the program needs to keep in mind when a process is changed that patients need to be consulted about the change first (April 2014) -Angela is following up with Susan Scott about the transfer set being displayed at each PD education visit (May 2014) -Paul is following up audiotapes for dialysis patients and will pursue his contact, and report back at the next meeting (July/September 2014) -the cable at KCC will be reinstated as soon as Roger's Cable can come -waiting room TV's being used for education and advertising -Angela has put a copy of the council brochure in each "My Care" binder at CKD clinics, and the clerks in the clinic have agreed to replenish the new binders when they are created 	<ul style="list-style-type: none"> -Angela will put brochure, a copy of the newsletter, a poster on the boards, and anything else supplies by the council -Don, and Nancy volunteered to be trained, George will follow up with Anne Brinkman -George will e-mail concerns to the PEP project - we will follow up later with this
5.1	Welcome Dr. McIntyre and PFCC Experiences	<ul style="list-style-type: none"> -our newest council member, Dr. Chris McIntyre was welcomed to the council -Dr. McIntyre is a research Nephrologist and has recently 	

<p>5.2</p>	<p>Report on ORN PFAC Summit</p> <p>Possible future topics (from Bonnie as a result of the Summit):</p>	<p>moved to LHSC and Canada from England, and brings a wealth of knowledge and experience in patient and family centred care</p> <ul style="list-style-type: none"> -along with Dr. Rehman, Chris will represent the physician part of our council -he would like to get the council involved in the research part of nephrology, and to involve the council in recruiting patients to join research studies that are designed to improve dialysis, that are simple and improve the way people feel -another area of research that Chris is involved in focuses on the part of a dialysis patient's life when they are not at dialysis, in-between treatments. This research will combine art and how a patient sees their life between treatments through the lens of a camera -another area of study involves patient input on the design of a dialysis machine -a research forum is planned in early 2015 for the multidisciplinary care team which Chris would like the council heavily involved in to set the research agenda in motion <p>-Cancer care Ontario and Renal Network had a PFAC summit on November 10 in Toronto, Bonnie, Mike, George and Janice attended, and George and Janice made a short presentation about "Best Practices and Lesson's Learned"</p> <ul style="list-style-type: none"> -there was a great response, and in George's words "There was some envy at how far we have come in London" <ul style="list-style-type: none"> -How can we recruit some family members to join the council? -Hearing Staff Stories -Having a suggestion box or results notice, and ask patients "Would you be willing to share your story?" -Poster : "The next generation of kidney care begins with you" -Develop patient resource centre in patient waiting rooms -Are we pursuing WIFI for patients? 	<ul style="list-style-type: none"> -Dr. McIntyre will come back to the council with a questionnaire about machine design, as well dates for the Research Forum -presentation slides attached -there is one new family member interviewing in January, we could also have a council member visit the units to ask families to join
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6.1	Housekeeping	<p>-Don shared his research from a printing company that can supply shirts for the council with our logo embroidered</p> <p>-Brian brought up the issue of staff in the dialysis units not wearing their flu masks correctly, and not wearing their name tags, Deb has asked that this be reported to either the unit Co-coordinator (UH Gail Barbour, VH Kim Farrow, KCC Linda Downing) or to Deb directly</p> <p>-George brought up increasing the length of the meetings to 2.5 hours when needed</p> <p>-Nancy suggested that each task group should have one person to write a report on what the task group has done in the last month, which is submitted to the chair and then distributed with the agenda to read before the meeting, so that the meetings can be primarily for discussion</p> <p>-Fred suggested that when points are brought forth the speaker be short and to the point to help save time</p> <p>-George reported that through his role in the Kidney Foundation, he has been appointed as the Regional Renal Program Steering Committee Member with our local LHIN</p>	<p>-Don will follow up with company</p> <p>-Angela will supply costs to Deb for approval</p> <p>-it was decided to keep the meeting length at 2 hours, but to extend on an if needed basis if quorum still exists</p>
6.1	Meeting Adjournment	<p><u>Next Meeting</u>: Tuesday January 13, 2015</p> <p><u>Advisor Orientation</u>: Tuesday January 20, 2015 5:30pm</p> <p><u>Story Telling Workshop</u>: Tuesday Feb 17 and Thursday Feb 19 at 5:50 to 7:30pm or Tuesday Feb 24 and Thursday Feb 26 at 5:50 to 7:30pm</p>	<p>-please let Angela know by December 31st if you will be attending the orientation</p> <p>-All new advisors are requested to attend, current advisors and staff members welcome also</p>