

RENAL PATIENT AND FAMILY ADVISORY COUNCIL MEETING MINUTES Tuesday December 13, 2016 5:00pm to 7:30pm Kidney Foundation Office

In Attendance: Fred McInnis (Chair), Paul Dixon (Vice Chair), Philip Varughese, Betty Clinton, Deb Bezaire, Angela Andrews, Anne Hutchison, Mike Smith, Bonnie Field, Don Smith, **Guests:** Dawna VanBoxmere, Janice McCallum

Regrets/Absent: Dr. McIntyre, Deb Beaupre, George Goodlet, Cathy DuVal, Robert Barnicoat, Viengkham Chanthalan Sy, Dr. Rehman, Nancy Wilder, Jarrin Penny, Nikki Anderson, Michele Ivanouski

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of November 8, 2016 approved as distributed.	
1.2	Additions to the Agenda	Add: Launch Program – Angela Andrews	
2.1	Accreditation: Patient and Family Involvement Dawna VanBoxmeer	Guest Dawna VanBoxmeer, Patient Safety Specialist from the LHSC Accreditation Committee presented the committee with information regarding Accreditation. Please see attached presentation for details.	Accreditation presentation Renal Pl
		An "onsite survey" is conducted every 4 years by Accreditation Canada. There are 23 standards of practice that are developed by Accreditation Canada to be used nationally to provide measures of excellence to improve patient and client care which hospitals can strive to meet. There are 31 ROPs (required organizational practice) that apply to LHSC.	Angela: Link "Accreditation" to the Renal Patient Website

3.0	Task Group Reports		
3.1	Patient Resource Task Group	Philip reported that some of the categories for the resource tower will include fall prevention, safety in home, nutrition, diet, exercise and doctor/patient relationships. Deb suggested meeting with Dietician, Social Work, Pharmacy and Nurse Case Manager to review what information rather than creating new documents.	Angela to arrange meeting with each group. Angela will send out list of questions for patients.
3.2	Communications and Patient Feedback Task Group	Cathy has resigned as leader however; she will continue to sit on the task group as a member. Dialysis unit visits are continue and going well. Canceled Dec 13 & 14 visits, will be rescheduled in the new year. The task group will share feedback with council as to what is being expressed by patients.	questions for patients.
		Fred brought forward a suggestion of having posters in the unit/clinics to include pictures and description of health care members.	POF_
3.3	Patient Transportation Task Group	Fred has written a reply letter to the LTC (London Transit Commission). Philip suggested including a follow up time frame (e.g. response within 30 days).	Reply Letter to
3.4	Newsletter	Kidney Kronicle distributed to staff and email subscribers. Hard copy will be mailed out by Christmas.	LTC.pdf
3.5	Recruitment & Orientation Task Group	Don is working on a survey for new orientees.	
3.6	Patient Experience Coordinating Committee (PECC)	Continue to work on a draft definition of patient engagement for LHSC. Patient Experience office held open forums for physicians, leaders and Patient Experience Coordinating committee. Each group was given several definitions of patient engagement and patient experience for review and feedback. Results of these sessions were reviewed at last meeting.	
3.7	Patient Safety Task Group	Also, the video of Bonnie's story (https://youtu.be/yEwu0RfLMPU) was shared with the committee. Positive feedback received.	
		Fred suggested we create a separate task group to educate patients about safety, medication, home safety and fall safety. Alternatively it was decided to include this information in resource centre material.	

4.0	Open Discussion		
4.1	Council Business Update	Cathy Duval has stepped back from being the leader of the Communications task group for personal reasons, as well as to observe the workings of a task group, and may accept the role later on	Philip (resources task group) will include the review of current learning material for
		George Goodlet has been granted a Leave from the council for personal reasons until June 2017	review in task team agenda.
4.2	Hip Chat	Deb shared that the director of Corporate communications has denied the request of council to use HipChat as a forum to discuss PFAC business or start a support room for PD and Home Hemo patients	Illness-Health_PubHu m-nov2016-lowres.pc
4.3	Refreshments at meetings	due to the fact that HipChat cannot be guaranteed to be secure. Reduce the amount of food being ordered.	Next meeting Angela will order fruit and drinks.
4.4	Electricity assistance for home hemo patients, process and access	See 4.11	
4.5	How to contact social work staff, protocols	Patients are encouraged to speak to the unit nurse to contact social work allied health staff.	
4.6	LAUNCH	Angela shared a request from Carolyn Ingram and the BAID team working with her regarding the LAUNCH (Learning about You New to Chronic Hemodialysis) program. The program involves the development of consistent, comprehensive practices and education for people new to hemodialysis making decisions for their care such as dialysis choices, vascular access, transplant and self management. Other centres in Ontario have provided this care by having a designated 'new start chair' in hemodialysis units which focus on designated staff with specific goals for teaching and supporting patients new to hemodialysis. Our program will not be a designated space in one particular unit but will be a virtual chair which follows the patient through their CKD journey. Patient education will not be limited to the physical location of the patient; rather preceptors will be trained and able to respond to patient learning needs at all dialysis facilities as learning needs arise. For example, if the patient starts hemodialysis at the acute care centrel and then within 2 weeks is transferred closer to home to the satellite hemodialysis unit there will be skilled and motivated staff in each unit to help the	

patient adjust to hemodialysis and assist with decisions regarding their care.

The whole idea is the content will be patient driven, in 20 min sections. Patients will have a listing of the titles of the sections and they will get to choose what is most important to them to learn.

There will be nurses from each unit, including satellites who will have spent a day of education, as well as armed with back up support, (me) to deliver the content. The spirit is to be patient centred, with the RNs armed with info re: health literacy, and appreciative of the fact patients need evidence based education in order to make good decisions for themselves. We intend to include the lab sheet, rejigged for HD that the patients worked on for pre-dialysis.

The topics include infection, dialysis access, HHD, PD transplant including living related, sex. Social supports. The content is not necessarily strictly our manual, but also include some video snippets, the KF manuals, diet, foot care, and activity. The idea being that this would replace the 15 something pamphlets that we currently give out.

On behalf of the program, Carolyn has requested that the pfac review the educational content, and we will be getting the information packet to you in January.

Janice updated us on ORN business, including the ORN patient engagement plan (attached) that includes a dashboard of what all the other renal programs in the province are working on related to person centred care and patient engagement

Angela and Deb submit info twice a year to the ORN about our patient engagement activities. LHSC has been highlighted on the plan with our storytelling activities and storytelling orientation for advisors

The ORN had talked of starting a provincewide PFAC website for advisors to communicate with one another, but have changed direction and have moved to a social media platform instead that all PFACs across the province can access

ORN has procured an agency to perform patient experience surveys that have statistical significance for renal programs across the province, it's called NRC Picker, we will be trialing this in our program

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4.7 ORN updates

		twice a year, we may have first survey completed in the spring of 2017	
4.8	Naming of CKD Clinics	The ORN executive committee has approved a name change of all CKD programs across the province to be renamed Multi Care Kidney Clinics (MCKC), this was done on suggestion of the ORN PFAC. "Multicare Kidney Clinics" (MCKC) is the new name, approved by ORN Executive Committee. This new name will be phased implementation in 2017.	
4.9	ORN Workgroup	ORN workgroup looking at patient bourne costs in hemodialysis; with a focus on home hemodialysis. As a response from the Ministry of Health, looking at making recommendations around addressing patient bourne costs (e.g. water, electric, waste removal and travel). Looking at municipalities across the country.	
4.10	Save Your Veins Campaign	Fred will follow up with the Renal Executive Committee regarding the resources available/designated to keep the momentum of this campaign.	
4.11	Storytelling	Bonnie suggested having a storytelling as a standing section to agenda for each meeting.	
4.12	Discharge Summaries	Bonnie is involved in a focus group looking at discharge summaries. The idea is to give inpatient/outpatient visits and emergency visit summary to patient to summarize each visit. Hope is to roll out in spring of 2017.	
5.0	Housekeeping		
5.1	Next Meeting Date	Tuesday January 10, 2017 5:00pm to 7:30pm, Kidney Foundation Office	