


**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday June 13, 2017
5:00pm to 7:30pm
Kidney Foundation Office**




In Attendance: Fred McInnis (Chair), Philip Varughese, Betty Clinton, Angela Andrews, Don Smith, Nancy Wilder, Viengkham Chanthalan Sy, John Witteveen, Michele Ivanouski, , Anne Hutchison, Dr. Rehman, Bob Barnicoat, April Mullen, George Goodlet

Regrets/Absent: Dr. McIntyre, Nikki Anderson, Mike Smith, Cathy DuVal, Emma Klotz, Janice McCallum, Paul Dixon (Vice Chair), Bonnie Field, Jarrin Penny, Deb Beaupre

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of May 9, 2017 approved as distributed.	
1.2	Additions to the Agenda	2.2: PREMS, 4.2 Patient Experience outside of renal, and 4.3 Save your veins	
1.3	Patient Story Telling	-Don shared his kidney journey story with the council	
2.1	Our People Survey Results- April Mullen	-April shared the results of the Our people survey that was conducted by the LHSC for it's employees -%60 of staff responded, see attachment for the results of the survey -ALU and UH will be using their CQI's to identify and work on the problem areas, Communication being one of the areas, KCC has not come up with a working plan yet -senior leadership will also create action plan to deal with unsatisfactory results scored by the senior leadership team	 OurPeopleSurvey Presentation_PFAC.p
2.2	PREMS- April Mullen	-PREMS, (Patient Reported Experience Measures) is going to be conducted by NRC Health	

		<p>(previously NRC Picker) on behalf of the ORN</p> <ul style="list-style-type: none"> -they are looking to gather information from renal patients across the province around 2 main topics, including patients being informed about treatment options and patients and families being offered the opportunity to be involved in the development of their individualized care plan -promotional materials for the survey will come to the renal units in June, and the program will supply to the ORN the address of the targeted patient groups, who will then mail out the survey in July and August -the final reports will be sent to the ORN in November -the ORN plans to do this information gathering yearly 	
3.0	Task Group Reports	<ul style="list-style-type: none"> -the task groups met and created plans for the work that will be done in the coming year, the group discussed the plans and laid them out in a time line for completion 	
3.1	Patient Resource Task Group	<ul style="list-style-type: none"> - there needs to be a continuous improvement plan for the resource centre - a foundation has been laid and based on council and patient feedback, we can continue to expand the scope of the resource centre - the pfac will recommend a systematic review of all of the different educational information that is provided for kidney patients from the LHSC renal program starting from when patients are first diagnosed with CKD all the way through to transplant -the PFAC vision is to have the pfac providing continual educational resources for patients that is relevant and up to date information 	
3.2	Communications and Patient Feedback Task Group	<ul style="list-style-type: none"> -Cisco Jabber not available for non-employees -Angela spoke with Mary Gillet, the Director of Corporate Communications. A link to “Hip Chat” would be allowed on the Renal PFAC webpage, but the “hip chat” discussion group can not be in any way affiliated with LHSC, including the Renal PFAC due to privacy and liability of LHSC. -For example, If Philip wanted to be the host of a discussion group called “support between home dialysis patients” that would be allowed, but he could not mention the PFAC or LHSC, so he couldn’t spread our PFAC news letter or bring info back to the PFAC that is discussed on the group. -the reason that LHSC does not support Hip Chat is to do with trolling by 3rd parties (often done by a computer) where the words and conversations of people in the group are monitored and recorded, 	

<p>3.3</p>	<p>Patient Transportation Task Group</p>	<p>for example, say a member of the group talks about abortion, then suddenly that person's home computer become inundated with adds for abortion. LHSC would have no way of monitoring hip chat for privacy and use of trolls, so could potentially be liable for a breach of privacy of a patient</p> <ul style="list-style-type: none"> -the council decided not to pursue the creation of a hip chat support room due to hospital liability issues and the continued negative response from the communications department -we will place an add in the next newsletter that mentions Hip chat and that if patients are interested in a communication tool to contact one another they can can look into hip chat <p>-The survey monkey survey regarding a patient education day that was advertised in the newsletter and at the waiting rooms of dialysis units was not very successful, in that we only have 6 respondents. The group decided to send out a survey for home patients, satellite patients and in-centre patients and the council was given a chance to review the survey</p> <ul style="list-style-type: none"> -the council decided to hold another task group meeting to rework the survey and then it will be mailed out with the newsletter in August to cut down on cost of mailing it out <p>-Fred has agreed to submit a proposal to Janice over the summer regarding revisiting the satellite units, if Janice approves the proposal we will start the visits in September</p> <ul style="list-style-type: none"> -the group discussed patient feedback on the new paratransit booking system, there have been less complaints over the last few days that Bob has heard at Westmount HD. -the group plans to invite paratransit representatives to meet with pfac again in the fall to review the 4 presented issues and solutions provided by LTC -the group also plans to review and gather data on transportation other than paratransit used by in and out of town patients, and PFAC plans to take up the offer of having a PFAC representative on the LTC advisory committee in September 	<p>-Angela will set up task group meeting to rework the survey in the next few weeks</p>
<p>3.4</p>	<p>Newsletter</p>	<ul style="list-style-type: none"> -next newsletter goes out in August, we will send the pt. education survey at the same time -many articles in the works, including a Who's who from the Charge nurse at UH, as well as some info promoting the use of hip chat, as well as a suggestion to ask patients what they want to see in the newsletter , a 'Meet The Council" with a picture and names of those on the council, as well as 	

<p>3.5</p>	<p>Recruitment & Orientation Task Group</p>	<p>more patient stories</p> <p>-nothing to report</p>	
<p>3.6</p>	<p>Patient Experience Coordinating Committee (PECC)</p>	<p>-nothing new to report</p>	
<p>4.0 4.1</p>	<p>Open Discussion Emergency Preparedness- Anne</p>	<p>-Anne has been involved in the emergency preparedness committee (EPC) for the Renal program, She shared several documents for the pfac to review regarding the emergency preparedness manual and information for patients</p> <p>-several comments were brought forward to Anne to bring to the emergency preparedness committee including:</p> <ul style="list-style-type: none"> -Appendix J: we would like more clarification around communications for "pre-emergency" and what does this encompass, especially for those not on line or without phone access? - some more information around how patients will be communicated with during an emergency (i.e.: if a power outage how will patients be able to find out where they have to go for dialysis if the don't have a cellphone or have cordless but no landline)? - should patients have copies of their treatment prescriptions to take to other units if required? - what are transportation plans for hemo patients who are not mobile? <p>Communications/Training Primacy:</p> <ul style="list-style-type: none"> - how will the Emergency Planning education be provided to the patients - in-house hemo, at-home hemo and at-home pd? - can the info be encapsulated in a document and be provided to patients by the caregivers (i.e.: staff)? - would it be helpful for PFAC to post info on our communications boards or provide handouts? - will info be included in My Care or Launch binders? 	  

4.2	Patient Experience outside of the renal program- George	<ul style="list-style-type: none">- what about patients already in the system who do not have binders? Home-Hemo patients: <ul style="list-style-type: none">- do home-hemo patients know how big their generators should be to withstand a power outage?- if necessary, can home-hemo machines be used as backup for other patients? <ul style="list-style-type: none">-George shared some of the LHSC health experiences that he has had outside of the renal program-he started by saying that when he experiences care outside the renal program, he is reminded that the renal program is exceptional-he encouraged that transplant patients be well informed about their illness, especially their medications-George also wanted to bring attention to the fatigue and stress that patients experience when dealing with illness, and how these symptoms are compounded when dealing with multiple illnesses-he discussed the long wait times for appointments, and suggested that the renal program try to minimize different appointments-George suggest waiting areas are inadequate for family members-patients are frustrated with being asked the same questions over and over by different staff members within the same clinic (eg pt's height, medication list etc.) when it's already written in the chart-George is also frustrated that there is no direct link to contact a physician, if patients call with a question it goes through several staff members first to get to the physician, he is concerned that the full message or question may be distorted by the time it gets to the physician, and is suggesting a direct link be available to physicians-George would also like to be given the choice as to whether he is called in the waiting room by his name or as a number, he feels that being called by a number is too impersonal-April suggested that Sandy Jansen from the patient experience office would benefit by hearing George's experiences, Fred suggested that George put his story on paper	
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4.3	Save your veins- Don	-Don recently had bloodwork taken at Dynacare labs, and they were telling him that renal patients would come with a bright yellow paper that instructed the phlebotomists to use hands veins, but that patients have not been doing so recently, the lab staff wondered if the save your veins program was discontinued. Don informed them that the ORN was looking into the revamping of the save your veins initiative and that they would hopefully hear more soon.	
5.0	Housekeeping		
5.1	Next Meeting Date	Tuesday September 12, 2017 5:00pm to 7:30pm Kidney Foundation Office	