



**RENAL PATIENT AND FAMILY ADVISORY COUNCIL  
MEETING MINUTES  
Tuesday February 13, 2018  
5:00pm to 7:30pm  
Victoria Hospital Room B2-124**

**In Attendance:** Bonnie Field (Chair), John Witteveen, April Mullen, Janice McCallum, Don Smith, Jim Harrington, Angela Andrews, Nancy Wilder, Cathy DuVal, Bob Barnicoat, ,Deb Beaupre, Anne Hutchison

Guests: Barb Wilson, and Lori Harwood, Renal Program NPs, and MaryBeth Billick, Patient Experience Specialist



**Regrets/Absent:**, Betty Clinton, Michelle Ivanouski, Nikki Anderson, Emma Klotz, Dr. Rehman

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of January 9. 2018 approved.	
1.2	Additions to the Agenda	3.7 Patient Experience Week- Don	
2.1	Patient Centred Research	-Lori Harwood and Barb Wilson, both Nurse practitioners in the Renal program shared some of the patient centred research that was completed in the Renal program called “Reaching Consensus on Outcomes for Successful Needling of the AVF: Patient and Healthcare Provider Perspectives” to describe what healthcare providers and people on hemodialysis consider as outcomes for successful cannulation of the AVF -the pfac members felt is was a good idea to have patients come in for	 <b>Accreditation presentation Renal PI</b>

<p>2.2</p>	<p>ORN Report on Patient Experience Surveys</p>	<p>their first dialysis appointment and not have dialysis, just to have the fistula looked at and mapped out and prepared for needling the next visit</p> <p>-April reported on the ORN Patient Experience Surveys that were completed by select renal patients in September 2017</p> <p>-Two Patient Experience Surveys were sent to kidney patients to better understand experiences with regards to:</p> <p><b>Treatment Options &amp; Shared Decision-Making</b> – How many patients/families are engaged in making decisions about their kidney care and are informed about all of their treatment options including dialysis modality, conservative care, access and transplant?</p> <p><b>Chronic Disease Management</b> – How many patients and families are supported by their kidney care team to manage their chronic kidney disease</p> <p>-Two groups of patients were surveyed:          Group 1: Current MCKC patients in Ontario that are          Group 2: Current chronic dialysis patients in Ontario who started dialysis in the last 3-6 months from receiving the survey</p> <p>-London Renal Program Surveys sent was 609, surveys returned 119 for a 19.5% response rate.</p> <p>-results showed that patients felt better supported in decision making when they had had some type of renal education, such as the MCKC education classes, as opposed to no education, they also felt better informed and better able to make a decision and dialysis treatment options when they had already started hemodialysis.</p> <p>-patients in LHSC scored higher than the provincial average</p> <p>-the second survey looks at patient perceptions of interactions with the care team, again London scored slightly higher than the province in most areas</p> <p>-the areas that LHSC did not score higher on gives the program a</p>	 <p><b>2018 02 13 meeting attachment ORN Pati</b></p>
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		<p>starting point to improve their services, and out of this a Patient engagement plan was created.</p> <p>- <b>Patient Engagement Plans Submission</b>– Our Renal Program has incorporated learning on from the Patient Experience Survey results in how we can better engage and collaborate with patients and families at the local level. This was submitted to the ORN the end of January and will be shared with PFAC at our March meeting.</p> <p><b>PFAC</b> – opportunity exists to use this data to inform the work of our task group (i.e. education task group)</p>	<p>-we will discuss the patient engagement plan at the March meeting</p>
<p>3.0 3.1</p>	<p>Communications and Patient Feedback Task Group</p>	<p>-satellite visits to Goderich and Stratford made on January 31<sup>st</sup> by Angela, Betty and Don</p> <p>-no major complaints made from patients at either site</p> <p>-Goderich has made some significant improvements in their unit as far as patient confidentiality (installing a barrier for when staff is on a OTN call and discussing patients)</p> <p>-they have also used the very small space that they have wisely, installing a lift on the ceiling so it does not take up space</p>	
<p>3.2</p>	<p>Patient Education Task Group</p>	<p>-this group met on Feb 6</p> <p>-several education initiatives were discussed including the possibility of creating a patient Medical Journal for patients to carry to appointments</p> <p>-we discovered that most of the education patients are interested in is located in various documents given to patients from the program, also on the Renal patient web</p> <p>-group will likely function as a ad hoc group when needed, there may be opportunity for education work when the Patient engagement plan is put into action</p> <p>-this group will maintain the education towers also, and has discussed removing the rotating tower at the VH dialysis unit and putting the</p>	

		<p>information in already existing pockets on the wall in the hallway, and then move the rotating stand to be permanent in the UH Transplant clinic</p> <ul style="list-style-type: none"> <li>-Jim suggested moving the rotating stand at KCC up to the front waiting room for a while, he has confirmed with Margaret at the front that there is space</li> <li>-Anne suggested that the bulletin boards on the walls in the main waiting room need to be kept up to date (e.g. foot check dates, med review dates), sometimes when things are not kept up to date, the patients don't look any further at the PFAC information</li> <li>-a patient family member volunteered to update things, add some colour, Anne will touch base with her</li> <li>-Jim suggested that we need a comments box on the transplant clinic stand, April will order.</li> </ul>	
3.3	Patient Transportation Task Group	<ul style="list-style-type: none"> <li>-Don has begun work on a letter to paratransit asking for a meeting to discuss any changes made since last April.</li> <li>-we have not heard back from the ORN PFAC regarding the letter Bonnie sent asking if they are working on transportation issues, Angela will look for a ORN PFAC email address and try to send it that way too</li> </ul>	
3.4	Newsletter	<ul style="list-style-type: none"> <li>-due to go out end of February, will contain articles on Tax credit info for dialysis patients, the new LAUNCH manual, and home hemo water/electric grants, a "what's happening in dialysis" section and world Kidney day advertisement</li> </ul>	
3.5	Patient Experience	<ul style="list-style-type: none"> <li>-Angela and Bonnie met with reps from the patient experience to discuss our pfac and it's success</li> <li>-PECC will no longer run, but there are plans to get a corporate</li> </ul>	

<p>3.6</p>	<p>Other committee reports:                  Parkwood Project</p> <p>Emergency preparedness</p>	<p>committee that involves patient/family advisors</p> <ul style="list-style-type: none"> <li>-the Patient Experience dept has been revamped and they have many plans, and would like to re-bond with advisors</li> <li>-several ideas discussed regarding a possible orientation session for new advisors, the plans for LHSC to recruit over 600 advisors for local committees and corporate strategy, patient forums and advisor gatherings with advisors from all over LHSC</li> <li>-new Framework being chosen to model person centred care at LHSC, and Patient and family input is embedded with accreditation</li> <li>-there is a Patient Experience Forum to find out more March, 20 130 to 3pm, and another on March 24<sup>th</sup> 4:30pm to 6:00pm</li> </ul> <p>-April reported that the dialysis unit at Parkwood will open on Feb 21<sup>st</sup> and have 2 patients for the first week, then for the second week they will be fully operational at 5 patients. It was previously planned to have just rehab patients, but it's been since identified that there are also veteran patients and complex care patients that would benefit from use of the unit as well, so to remain a patient centred unit, patients will be put on a wait list for Parkwood based on their start date, and not prioritized based on the category of care they are under</p> <p>-staffing will be completed by VH dialysis</p> <p>-Anne provided copies of the new emergency preparedness pamphlet specific for dialysis patients, that was created with assistance from Anne, Bonnie and Don and a poster.</p> <p>-links for both of these will go on renal patient website</p> <p>-pfac would like to complete a more general emergency preparedness pamphlet that they can adapt from the general LHSC pamphlet. Angela will provide an electronic copy of the general LHSC pamphlet to Anne so that they can adapt it</p>	 <p>EMP patient communication pamphl</p>  <p>Poster- Planning for an emergency-.pdf</p>
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		<p>locations</p> <ul style="list-style-type: none"> <li>-there will be a display at all 3 sites, UH, VH, Westmount</li> <li>-MaryBeth suggested that Renal PFAC would possibly like to have a booth to advertise our council as well</li> </ul>	
4.0	Open Discussion		
4.1	Kidney Foundation Financial Burden Survey	<ul style="list-style-type: none"> <li>--the Kidney Foundation completed a survey in January regarding the financial burden of patients on dialysis</li> <li>-looking forward to hearing the results</li> </ul>	
4.2	World Kidney Day	<ul style="list-style-type: none"> <li>-World Kidney Day is March 8, 2018</li> <li>-the theme this year is Women's Health</li> <li>-three different sites for display are planned in conjunction with PFAC and Kidney Foundation</li> <li>-YMCA downtown 9 to 12, Victoria Hospital B2 Atrium 9-4, and Movati Athletic club North 4-8pm</li> <li>-a patient will share her story of being pregnant while on dialysis</li> <li>-the communications department is interested in having the media attend, and will take photos for the day at VH</li> <li>-we will be giving out pens on the day to patients and visitors to the booth as well</li> </ul>	-
4.3	Mailing to Patients vs. Email	<ul style="list-style-type: none"> <li>-Bonnie mentioned that she gets mail outs from the home hemo clinic regarding appointment reminders or updates. She is concerned over the cost of the mail out, could they not do updates and things like this by email instead</li> <li>-April suggested it might be because we already have a list of pt. addresses collected, and it might be easier to pull that list than email, there is also a consent form that has to be signed by the patient before</li> </ul>	

		information can be exchanged via email -April will bring this feedback to the management meeting to discuss	
5.0	Housekeeping		
5.1	Summary of Action Items		
5.2	Next Meeting Date	Tuesday March 13, 2018 at 5:00pm at <b>Victoria Hospital room B2-124</b>	