



**RENAL PATIENT AND FAMILY ADVISORY COUNCIL  
MEETING MINUTES  
Tuesday April 10, 2018  
5:00pm to 7:30pm  
Victoria Hospital Room B2-124**

**In Attendance:** Don Smith, Jim Harrington, Angela Andrews, Cathy DuVal, Betty Clinton, Michelle Ivanouski, Johanna Lane, Anne Hutchison, Nancy Wilder, Bonnie Field (Chair), April Mullen, Kathy Austin, Minoo Hatami, Guest: Don Bester








**Regrets/Absent:** Nikki Anderson, Emma Klotz, Dr. Rehman, , Bob Barnicoat, Deb Beaupre, John Witteveen, Janice McCallum


	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes from March 13, 2018 approved	
1.2	Welcome to new members	Round table introductions completed as several new members in attendance Welcome to Cathy Austin, RN from the Westmount Hemo Unit, and Minoo Hatami, family member	
1.3	Additions to the Agenda	4.6 Interview Questions for Leaders 4.7 Planning meeting	

<p>2. 1</p>	<p>Integrated Dialysis Care Project-Don Bester, Renal Program Manager</p>	<p>-Don Bester, Renal Program Manager presented the Integrated Dialysis Care project to the group</p> <p>-ORN brought forward to programs in the province the idea of adopting a new model of care for PD (peritoneal dialysis) programs, LHSC has chosen to participate in this project</p> <p>-the current model provides some PD patients with in home PD support from staff from the LHIN (previously CCAC), however the care is not consistent or individualized for the needs of the patient</p> <p>-the new model aims to partner with a new agency, Paramed and will supply more consistent, individualized care to support patients in their home for PD with PSW's, RPN's or RN's (depending on the patient needs) which could extend as far as having a health care provider in the home for the entire period of treatment if the patient requires it</p> <p>-the second phase of the program will also extend support to patients who live in long term care homes as well</p> <p>-the goal of this project is to:</p> <ul style="list-style-type: none"> <li>• improve the patient and caregiver experience by increasing continuity and trust with more consistent staff</li> <li>• to decrease the rates of patients who stop doing PD (attrition) and return to in-centre hemodialysis by increasing the level of expertise of staff and increasing the consistency of staff with patients</li> <li>• increase home dialysis rates and likelihood that patients will stay home for PD because they feel more supported</li> <li>• increase the availability of PD for patients living in long term care homes (previously patients in LTC homes have not been offered PD because of lack of support, so they have been restricted to in-centre HD)</li> </ul> <p>-implementation of the project will begin when the Paramed agency has been approved by the Ministry of Health</p> <p>-the question was asked if this would be extended to home hemodialysis, Don responded currently this work is going on in other programs in the</p>	 <p>2018 04 10 IDC          PFAC Presentation by</p>
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<p>2.2</p>	<p>Patient Engagement Plan-April Mullen</p>	<p>province, but LHSC will concentrate on PD only at this point, he also commented that there is a lot more training involved for the home hemodialysis program, and it may not be as optimal as PD</p> <p>-April presented the work/planning that has been done within our program for the Renal patient engagement plan that is submitted quarterly</p> <p>-the main engagement plans centre around:</p> <p>Education Training and Resources for Staff:</p> <ul style="list-style-type: none"> <li>• Vital Behaviours (VB) that demonstrate the principles of PFCC were developed across all disciplines. Staff committed to demonstrating these behaviours in all interactions with patient and families. VB will be revisited/updated and a sustainability plan put in place throughout the program.</li> <li>• Based on ORN Patient-Reported Experience Measures survey results that values and traditions should be considered in treatment decision all leaders within the Regional Renal Program will complete the Aboriginal Cultural Competency Training course through CCO.</li> </ul> <p>Education Training and Resources for patients and families:</p> <ul style="list-style-type: none"> <li>• PFAC member, staff and leadership will attend a 4 day educational conference at the Institute for Patient and Family Centered Care Spring 2018 to present and will share their learnings with PFAC and across the Regional Renal Program.</li> <li>• Based on ORN Patient-Reported Experience Measures survey results that patients want a communication of their treatment plan the PFAC education task group will assess the creation of a patient journal.</li> </ul> <p>Peer Support</p> <ul style="list-style-type: none"> <li>• Implementing Transplant Ambassador Program as part of the Access to Kidney Transplantation project which provides peer support to potential kidney transplant eligible patients.</li> </ul> <p>Communication, Participation and Information Sharing-</p>	 <p>Regional Patient Engagement Plan Jan</p>
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3.0	Task Group Reports		
3.1	Communications & Feedback Task Group	<p>-Angela will ask Janice to touch base with the Hanover and Owen Sound dialysis units leaders to request a PFAC visit</p> <p>-Angela will arrange the visit for some time in late May, we will visit Hanover and Owen Sound in the same day to decrease amount of travel</p>	
3.2	Patient Education Task Group	<p>-as part of the patient engagement plan this group will begin some investigation work with the various clinics to find out the need/interest for a patient journal, Bonnie has set up a meeting with Sherri Bencich (RN in gen neph clinic) to discuss and then begin creation of the journal</p> <p>- Angela will set up a meeting space/time for the group</p> <p>-this group will also be responsible for creating a collection of information around community resources available to patients</p>	-Angela will arrange visit dates
3.3	Patient Transportation Task Group	<p>-the transportation task group has been invited to visit the LTC offices on April 25, to view the new computer system and discuss our previous meetings</p> <p>-the task group met to discuss previous questions and answers from the last meeting, and created a discussion plan for the meeting</p>	-Angela will set up meeting for group
3.4	Newsletter	-newsletter will be planned to go out prior to the Patient Experience week in June (June 18 to 22) so that advertisements for the week can get to	-please submit articles to Angela by May 15th

<p>3.5</p>	<p>Patient Experience</p>	<p>patients.                  -an article about the new pneumococcal vaccine coverage for renal patients will also be included</p> <p>-the patient experience office is in full swing again, and ramping up their activities                  -2 Advisor information forums were held in March, some topics included: (see attached document for full presentation)</p> <ul style="list-style-type: none"> <li>• The creation of 4 yearly events for advisors, 2 will be new advisor orientation sessions, and 2 will be advisor meet and greets for advisors from all over LHSC to get together</li> <li>• Work on a new Advisor portal that will be independent of LHSC, and will allow advisors to participate in chat rooms to stay connected</li> <li>• They are planning to recruit ~400 new advisors for all of LHSC to fully engage patients/families in all of LHSC, as well as meet accreditation standards</li> <li>• Several members from all PFAC's may be invited to make up an LHSC wide community council</li> <li>• Story Telling Workshops are being held again for advisors</li> </ul>	 PX Advisor Forum Slides 2018-03-20.pd  Memberships to the Beryl Institute.pdf  Patient Safety Incident Management  Surgical Care Signs 2018-04-06.pdf  Advisor Portal 2018-04-06.pdf 
<p>3.6</p>	<p>Other Committee Reports: Parkwood Project</p> <p>Emergency</p>	<p>-official opening of the Parkwood unit was end of March                  -things are going well                  -a group from the planning committee, including Betty are attending the Institute for Patient and Family Care conference in Baltimore in June to present their work on the Parkwood Project                  -Betty has stepped down from the committee</p> <p>-Anne is working on the general emergency preparedness pamphlet for</p>	 Storytelling Workshops 2018-04-

	preparedness	<p>patients</p> <ul style="list-style-type: none"> <li>-the EMP has been launched, staff are being educated about it</li> <li>-the pamphlet that Anne/Don/Bonnie created for renal patients is on the staff website and also on the patient website</li> </ul>	
4.0 4.1	Open Discussion Burden of Patient Cost/ORN PFAC	<p>-Bonnie was in contact with Mike McCormick from the provincial ORN PFAC who sent the Kidney Foundation Burden of Out-of-Pocket Costs for Canadians with Kidney Failure. The Kidney Foundation of Canada and the Canadian Association of Nephrology Social Workers (CANSW) partnered to administer a survey of Canadians on dialysis.</p> <ul style="list-style-type: none"> <li>- Kidney failure comes at high financial cost for many Canadians</li> </ul> <p>New report shows inequities in financial support for dialysis patients</p> <ul style="list-style-type: none"> <li>-Canadians living with kidney failure face significant financial challenges as a result of dialysis treatment. Starting dialysis often results in a decrease of income at the same time that out-of-pocket costs increase, such as those for transportation to treatment and medication. Government coverage and financial support for people on dialysis varies, resulting in inequalities across jurisdictions.</li> <li>- Recommendations made to ORN include:        Subsidize transportation costs and expand access to travel grants, particularly for people in rural areas.        Minimize disparities in accessing medications for people with kidney disease and develop mechanisms to offset costs equitably across jurisdictions.        Consider the financial and health literacy of patients when operationalizing “home first” policies that aim to maximize the proportion of patients on home dialysis therapies.</li> </ul>	<p><a href="https://www.kidney.ca/burden">https://www.kidney.ca/burden</a></p>  <p>Burden_of_Out-of-Pocket_Costs.pdf</p>
4.2	Change to meeting time	<ul style="list-style-type: none"> <li>-Philip Varughese has expressed interest in becoming active in the council again, and has made a request that we change the meeting time to 6pm to 8pm so that he can participate in the meetings</li> <li>-Angela will send out a survey monkey which will address meeting dates, times, location of meetings so pfac can have input anonymously</li> </ul>	

4.3	Patient Experience Week	<p>-June 18 to 22</p> <p>-Don is planning meet and greet with patients/managers/staff at Westmount daily, looking for pfac volunteers to attend an info booth daily, either 10am to 12noon, or 1pm to 3pm</p> <p>-let Don know when you are available</p> <p>-there are events planned all over LHSC for the week including education sessions for staff and a special appreciation day for advisors on the Friday to network</p>	<p>-Angela will send out a survey monkey which will address meeting dates, times, location of meetings so pfac can have input anonymously</p>
4.4	Save your veins	<p>-Don has joined the Nursing Professional Practice Committee (NPPC) as a patient advisor for renal. This committee is responsible for guiding nursing practice and policies and procedures</p> <p>-Don brought forward that this might be a good venue for assessing nursing knowledge about the Save your veins campaign and thought about surveying nurses on their knowledge</p> <p>-the group suggested Don bring this back to the NPPC and see if they agree with the practice of not using arm veins for blood draw on renal patients, and see how they would like to proceed</p>	<p>-please email Don with the dates and time you are available</p>
4.5	Review of PFAC ORP 3 Consultation	<p>-the group reviewed the answers given last meeting towards the ORP 3 consultation</p> <p>-the group commented that we did not fully answer question 1 around why we described renal care as fragmented, comments were we called it fragmented because of lack of communication between health care providers and patients, as well as between one other, also not all staff does things the same way</p> <p>-the group decided that they would like the questions by email to think about, and to have Janice facilitate a short discussion around the questions at the next meeting</p>	

4.6	Leadership interview questions	<p>-LHSC has plans to eventually include advisors on interviews for leadership team members, but this is not instituted yet</p> <p>-two interview questions were brought forward to pfac for their thoughts, however the group feels they did not have enough back ground info about the context of the questions, they would like the questions by email to look at, and then discuss at the next PFAC meeting</p>	
4.7	June PFAC Planning meeting	<p>-the group came to a consensus that they would like to have a facilitated planning meeting in June</p> <p>-the group was happy to have either an LHSC facilitator or Janice to facilitate the group</p> <p>-the group would like to move the meeting date to a week earlier, <b>June 5<sup>th</sup></b> to accommodate everyone attending, and also accommodate Janice to facilitate the group if needed</p>	
5.0	Housekeeping		
5.1	Summary of Action Items		
5.2	Next Meeting Date	Tuesday May 8, 2018 at 5:00pm at <b>Victoria Hospital room B2-124</b>	