

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL  
MEETING MINUTES  
Wednesday February 12, 2019  
4:00pm to 6:30pm  
UH B3-240**

**In Attendance:** Betty Clinton (Interim Chair), Bonnie Field (Interim Co-Chair), Ashley Roberts (Facilitator) April Mullen (Director), Lesley Pringle (Manager), John Witteveen, Kathleen Anderson, Deb Beaupre, Kathy Austin, Cathy DuVal, Don Smith (LOA)

**Regrets/Absent:** Pam Ireland, Dr Faisal Rehman (Physician)

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.0	Welcome, Approval of Minutes	-Approval of January 14, 2020 minutes	
2.0	Task Group Reports  1. Communications & Feedback Task Group  2.1.1	<u>Fall Satellite Visits:</u> Tillsonburg Visit on January 29 <sup>th</sup> , 2020. Patients are very pleased with the renal services they receive and the staff working in the unit. Reported not a great allied health presence. Transportation costs and travel an issue with some patients. Most patients utilize family or friends for transportation needs. Some patients use taxi services which is costly for dialysis visits. Unit has volunteer services come in to assist with making up	

	<p>2.1.2</p> <p>2.1.3</p> <p>2.1.4</p>	<p>“on &amp; off bundles” as well as providing patients with ice, blankets and conversation.</p> <p><u>Home Rates Improvement Action Pan: Meeting Feb.28<sup>th</sup></u></p> <p><u>Kidney Foundation Peer Support:</u> Platform uses different venues. (i.e. Internet and phone). There are multiple LHSC Privacy/Volunteer services barriers that we would have to navigate which would be very time consuming at this point. Having Kidney Foundation come into clinic would require MOA (memorandum of understanding).      April suggested a pause for present time and having no peer support in clinical setting; we can revisit in maybe 6 months down the road, depending on program capacity.      We agreed to move forward with in-person Peer support at Kidney foundation office once interest is generated from patients/families from our renal program.      Riz (our contact point from kidney foundation here in London) is on leave from foundation presently. Shannon Fogarasi is working on finding support for local London Kidney Foundation office.      Telephone and online support will be the resources available currently only. Kidney Foundation constructed a Poster focused on recruitment, which we will make available in clinical areas for patients and families.      Partnership intention kidney awareness and peer support.      April has shared experience with board.</p> <p><u>Patient Feedback Boxes:</u> Lesley acquired the patient survey from the LHSC cancer program. This worked well in the cancer program and feedback was given in the moment. The idea will be to collect responses regularly and follow up.</p>	<p>Ashley send out information for sign up for world kidney day.</p> <p>Lesley to revamp survey and send out to council for feedback.</p>
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2.1.5	<p><u>ALU Transitional Unit</u>: Looking at other areas who have this type of service. Purpose of project is to look at improving patient experience and improving home rates. The intention is that new dialysis patients would participate in a 4-8 week training program to explore what modality would be best for them with the hope that many will opt for some type of dialysis at home.</p>	
2.1.6	<p><u>Bulletin Boards</u>: Ashley and Daniela did walk around at VH and KCC. Looked at current resources for waiting areas and clinics. Daniela placed orders for more boards. Once boards come in, will bring back to PFAC to discuss which materials to utilize or how we want to utilize boards.</p>	
2. PFAC Newsletter	<p>Bonnie gave update. Working on Newsletter, daughter currently working on formatting for us.        Discussed ways for getting material. Educating staff on importance of newsletter. Next newsletter will hopefully go to publishing in the upcoming weeks.</p>	<p>Ashley to have conversation (meeting) with allied health.</p>
3. Recruitment & Orientation	<p>No updates</p>	
4. Diabetes Management Research	<p>No updates. Pam away.</p>	
5. Transportation Update	<p>-April provided update for Owen Sound/Grey-Bruce area: Funding was restricted from LHIN and could not prioritize medical patients. Manager is meeting with representative from the LHIN regarding the miscommunication. They asked our renal program to evaluate the volume of patients this impacted and would we be willing to have patients travel together to and</p>	<p>**Ashley to separate Local and Provincial for future</p>

3.0	<p>6. UF Control</p> <p>Other committee reports</p> <p>3.4.1</p> <p>3.4.2</p> <p>3.4.3</p>	<p>from dialysis. The most recent Update from today was that at this point in time we have no patients who require transportation back and forth to London.</p> <p>The LHIN has put a proposal into the ministry for vehicles and base salary for drivers and are waiting response.</p> <p>Our renal program is completing a review of patients travelling in for dialysis and will work to coordinate travel.</p> <p>The LHIN will complete a financial assessment: and may include a co-payment and subsidy depending on need. Selena Buma looked over the assessment and it is not any different than how we assess currently.</p> <p>-was brought up at renal executive. Julie-Ann Lawrence looking at evidence and will take it back to physician group for follow up. This was a pilot project initially.</p> <p>Issues with patients moving over to Westmount Hemodialysis unit that are profiled for UF at UH and complications with treatments.</p> <p>She will report back to renal executive council.</p> <p><u>Renal Joint Health &amp; Safety:</u> Discussed safety of nurses and staff. Small fire at Westmount, proper processes in place. Safe rooms at every site. Policy in place for both patients and staff.</p> <p><u>Renal Infection Control:</u> No updates</p> <p><u>KCC CQI:</u> Meets Monthly. Have not met since November. Meeting is next Wed Feb 19<sup>th</sup>, 2020.</p>	<p>Lesley can report back when information available.</p>
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3.4.4	<u>Renal Executive:</u> Meets once per month. No updates.	
3.4.5	<u>Renal Nursing Professional Practice:</u> Meeting end of February. No updates.	
3.4.6	<p><u>Renal Provincial PFAC Updates:</u> January 28<sup>th</sup> next meeting.          Out of country travel claims coming in and no issues presently.          A lot of discussion around Conservative renal care. How Acuity and Needs of patients starting dialysis are different from patients stopping dialysis.          Handout still a work in progress.          Goals of care discussion: will take place in first 3 months of treatment and annually, social workers are not comfortable having discussion without a physician present. London renal program is focusing on goals of care presently and will bring in conservative model once piloted in other areas and when we have capacity.</p>	
Open Discussion		
1.HMMS shadow day	Healthcare Materials Management System: how we acquire supplies and distribute to patients and facilities. We have asked about the possibility of staff at HMMS to see how dialysis takes place so they understand their role.	April will follow up next meeting
2. Genetics clinic	Informed patients of request from new physician for research project and gave background info on new clinic.	Ashley to follow up with Dervla and April (set up meeting)
3. World kidney day	World Kidney Day is March 12, 2020. Previous years we have worked with Kidney Foundation on a booth at KCC and VH locations. Currently seeking information from ORN and Kidney Foundation on support and materials.	Ashley will send out sign up request with times and locations

<p>4. Clinic lab results        Moved down to match up with note</p>	<p>Sent to renal nursing professional practice to vet through all disciplines. Make sure it is applicable for all areas. Next steps to vet through NCM and physician group.</p>	<p>Lesley can provide update when available</p>
<p>5. Emergency preparedness material update</p>	<p>Betty and Ashley touched base with Anne who worked on these materials and the ones available on the website are the more recent materials the committee worked on previously.</p>	
<p>Round Table</p>	<p>Kidney Link –ICES, patient-oriented research opportunities. Question was asked - does someone keep track of all the patients involved in research studies? Presently no system program wide. There are three divisions of research who track their own patients.</p> <p>St.Thomas kidney event: No kidney'ing around - transplant related event. \$20/ticket.</p> <p>Bonnie involved in dialysate magnesium research. Magnesium can affect muscle cramping. It is a randomized control study – LHSC will be involved. They are adjusting the amounts of magnesium in the dialysate and will evaluate whether or not it makes a difference with muscle cramping.</p> <p>Cathy discussed – new thyroid medication for patients, very expensive for patients; does not increase calcium; will chat with Lindsay Blackwell.</p> <p>-WHU heating/cooling issues, escalated to director of facilities and thought they were resolved.</p> <p>-fundraising: coins (western students used to do this) through United Way and used to raise a lot of funds. Question about raising funds for renal patient fund/emergency fund.</p>	<p>Bonnie to send link to Ashley</p> <p>April will look into this further</p> <p>April will bring to Suzy Webster (Manager)</p> <p>Ask Daniela re: fundraising</p>

		<p>-Choral group – singing in Westmount unit.          -Pet therapy</p> <p>Kathleen president of Metis committee here in London. Will bring forward coffee in community idea and give update when available.</p> <p>Bonnie mentioned possibility of entertainment in the hemodialysis units for patients. Suggested Huff and Puff Merry Makers (singing group)</p>	<p>committee as KCC or other areas.</p> <p>Cathy is connecting with Suzy (Manager)</p> <p>Kathleen</p> <p>Lesley to follow up at Volunteer Services meeting.</p>
	<p>Next Meeting Date</p> <p><b>Meeting dates and locations 2019/2020</b></p>	<p><b>Tuesday March 10, 2020 at Victoria Hospital Room B2-124</b></p> <p>-Meeting dates will alternate between Tuesday and Wednesdays starting in September 2019, and will alternate between KCC, UH and VH. The list of dates, times and locations is below:</p> <p>Wednesday April 8, 2020 at Victoria Hospital Room B2-124          Tuesday May 12, 2020 at Victoria Hospital Room B2-124          Wednesday June 10, 2020 at Kidney Care Centre Room 2111</p>	