

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL  
MEETING MINUTES  
Wednesday December 11, 2019  
4:00pm to 5:30pm  
UH B3-240**

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

**Regrets/Absent:** Kathy Austin



	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.0	Welcome, Approval of Minutes	October 9 <sup>th</sup> minutes approved, November meeting cancelled (not enough member attendance to meet corum).	
2.0	Additions to the agenda		
2.1	Blue Water Health: Palliative Care Helps Patients with Chronic Kidney Disease	<ul style="list-style-type: none"> <li>- Unit has a Palliative Care Partnership with the hospital palliative care team where practitioners come into the unit to see patients for pain management monthly.</li> <li>- Staff presented at CANNT conference (Canadian Association of Nephrology nurses and Technologists).</li> <li>- This program has inspired Chatham who also is looking into this program/approach; however, family physicians will be the partners.</li> <li>- Jackie Crandal (Adam Linton Dialysis unit (ALU) Nurse Practitioner has interest in this palliative care partnership approach.</li> </ul>	Ashley to look into CANNT poster presentation and potential call in from Sarnia staff to present poster.

		- The approach is more about living with symptoms of chronic disease and management.	
2.2	Renal Website Patient Forum	- We are looking for Patient and Caregiver input into the review of our current Renal Patient Website. Patients and caregivers are being invited to a forum with our Communications department to provide feedback on what content, information and format would be important to them in a website. We are hoping for patients from many stages of their End Stage Renal Disease (ESRD) journey, from early diagnosis, treatment decision and living with ESRD.	Ashley will follow up with Daniela and send out dates and session information when available.
2.3	ORN Patient Experience Survey Refresh: Local PFAC Feedback Forms	- Last year there were 2 surveys sent to patient homes. The ORN is looking for feedback from local PFACs on the two surveys. Feedback from patients last year was the surveys were to close, not enough time for actionable measures before the next survey is distributed, the grade level of content is too high, words/terms/language is not patient centered, and the content is not what patients want to be asked about. - ORN decided to take a pause on the survey- no survey this year. Instead they are asking local PFACs for feedback.	Ashley will ask April for surveys and feedback form. Ashley will send out to PFAC group in email format. Feedback/comments can then be sent back to Ashley. Ashley will compile responses and send back to ORN in one collaborative submission. Due Date: Jan 15, 2020
2.4	Volunteer at ALU	-ALU has had a volunteer for 17 years. She has not received referrals recently and did not feel valuable in the unit. She felt as though patients did not want to chat, they wanted to watch TV and feels like there is misunderstanding of her role or what is her role?	Lesley to follow up with Meagan Innes from Volunteer Services. As well as

		-Council member stated KCC also has a volunteer come in every Thursday for general chat. They feel she is valued there and patients like that she comes.	follow up and connect with ALU volunteer.
2.0	Task Group Reports		
2.1	Communications & Feedback Task Group		
	2.1.1	<p><b>Fall Satellite Visits</b></p> <p>-Betty provided summary on visits to Sarnia, Stratford, Chatham and Goderich.</p> <p><b>Sarnia:</b> In general, patients are satisfied with care and staff. Transportation costs remain a large burden for patients and families, multiple concerns with dialysis chairs and how uncomfortable they are, patient do not like arm banding practice, patients do not have pillows accessible to them.</p> <p>-Social work does not have large presence (majority of patients unsure of who social worker is).</p> <p><b>Stratford:</b> In general, patients are satisfied with care and staff. Transportation costs remain a large burden for patients and families, parking costs are \$25/month.</p> <p>-Social work does not have a large presence (majority of patients are unaware of who social worker is, so they ask nurse to contact her).</p> <p><b>Chatham:</b> In general, patients are satisfied with care and staff. Transportation costs remain a large burden for patients and families. Patients who qualify for ODSP are able to get coverage for transportation costs.</p> <p>-Patients were unaware of tax information for claiming transportation.</p> <p>-Patients who dialyze in the P.M. shift have to be accommodated to MID shift due to lack of transportation late at night.</p> <p>-Patients are now required to pay for monthly parking (\$20/month) where</p>	Ashley will provide April and Lesley with copy of satellite reports to date for leadership follow up.

		<p>before it was no charge.          -Social work does not have a large presence (majority of patients are unaware of who social worker is, so they ask nurse to contact her).</p> <p><b>Goderich:</b> In general, patients are satisfied with care and staff. Transportation costs remain a large burden for patients and families. Parking is free.          -Unit has volunteer come in for 1 patient.          -Unit does not have any curtains for separation between patients. They have access to one folding privacy screen and no separate isolation area.</p> <p><b><u>Home Rates Improvement Action Pan</u></b>          Meeting on Friday December 13, 2019</p> <p><b><u>Kidney Foundation Peer Support</u></b>          -KFOC (Kidney foundation of Canada) to take on the majority of the role to lead the project.          -Our role would be to help identify patients, and support processes in place to support KFOC presence          -Start with a survey/needs assessment. Could send it throughout the program and/or hand deliver. Looking at Potential for kidney foundation to come to LHSC (UH, VH &amp; KCC) sites for 2 days to target all patients and all three shifts, to educate patients and families about the Peer Support program and assess interests/needs for London Area.</p> <p>-Copy of redesign newsletter given to members. Thanks given to Bonnie and her daughter Kerri for the new look. Members were pleased with the new newsletter. Next issue will be sent out in March.          -Pam to provide Indigenous Kidney friendly recipes for distribution in future newsletters.</p>	<p>Bonnie to report back at next meeting.</p> <p>April and Kathleen will give running updates when available.</p> <p>Ashley will mail out newsletter to home programs, satellite units and give copies to Hemodialysis units to be distributed as</p>
2.1.2			
2.1.3			
2.2	Newsletter		

2.3	Recruitment and Orientation	<p>-Bonnie and Leadership have okayed the use of the photo collage poster picture for use on future PFAC recruitment advertisement materials.          -Recruitment form provided by patient experience office to help with recruiting.</p>	<p>well as leave copies in clinics and waiting rooms for patients to take.</p> <p>Ashley to send out previews of posters to group for approval and will distribute the recruitment form to physicians, social workers, pharmacy, Nurse case managers, vascular access, charge nurses as well as nurses in clinics including transplant.</p>
2.4	Other committee reports	<p><u>Renal Health &amp; Safety</u>: Meet once every other month.          Meeting cancelled. T-Con was not working. Next meeting January 22, 2020</p> <p><u>Renal Infection Control</u>: Meets once every other month.</p> <p>Question raised in Chatham whether flu shots can be given safely during dialysis. The answer is yes.</p> <p><u>KCC CQI</u>: Meets monthly.          Staff to be given survey on home dialysis to assess knowledge level when educating and promoting home dialysis. Was also done last year and staff</p>	
3.4.1			
3.4.2			
3.4.3			
3.4.4			

		<p>knowledge was not at level program would like.          -Christmas door decorating contest on hold due to hospital fire safety rule. Patients and staff were upset at this decision. Cathy spoke to Chris in patient relations who was unaware and has yet to respond back with information.          -Patient Log Book: the council approved the smaller size. They are now waiting on quotes and format decisions for printing.</p> <p><u>Renal Executive:</u> Meets once per month.          Nothing to report.</p> <p><u>Renal Nursing Professional Practice:</u> Meeting cancelled.          Coordinator assigned council retired. Last meeting was held in May.          Terri Chanda to take over council.</p>	<p>April to follow up with CQI re: printing</p>
3.0	Open Discussion		
3.1	<p>Washing Your Access</p>  <p>Washing your access 1.2.docx</p>	<p>-Asked to present letter to council by Kari Matos (Vascular access Nurse) for review.          -Multiple concerns were raised with regards to accessibility of sinks to patients as well as workflow for patients and staff.</p>	<p>Lesley to follow up with Kari for more context, research/literature on “why” the practice changes. Lesley to then connect with Kari and Betty regarding letter.</p>
3.2	Out of Country Dialysis Update	<p>-April informed group that funding and resources will now be provided and administered through the ORN as of January 21, 2020. Rates for reimbursement remain unchanged at \$210 per treatment. Bonnie is advocating for revision of rates (increase) as rates have not been increased in 30 years.          -ORN still developing process for managing reimbursement. Patients will have</p>	 <p>ORN Out of Country Dialysis.pdf</p>

<p>3.3</p>	<p>Renal Provincial PFAC Updates</p>	<p>to fill out claim forms, mail to ORN, the ORN then reviews, and ensures patient has OHIP coverage and they are requesting appropriate treatment. Reimbursement will take roughly 6 weeks.</p> <ul style="list-style-type: none"> <li>-Bonnie attended 2 meetings.</li> <li>-Rebecca Harvey stated the focus was on the transition of the ORN to Ontario Health             <ul style="list-style-type: none"> <li>- discussed out of country dialysis</li> <li>- ORN has asked the ministry to support funding for travel</li> <li>- ORN is looking into developing materials for patients in regard to conservative care discussions.</li> </ul> </li> <li>- Provincial ORN community of practice was to start in January of 2020 (currently on Hold)</li> <li>-PFAC in Kingston is now incorporating a newsletter into their tasks, based on how we present ours.</li> </ul>	
<p>3.4</p>	<p>Local Patient Experience Survey</p>	<p>April reported our patient feedback boxes have no pens, paper available, etc. for patients to fill them out. ?questions not meeting patient needs and need to be maybe more modality specific for increased engagement.</p> <p>-example: bifold surveys for patients to fill out and leaders go around weekly to collect and address concerns.</p>	<p>Lesley to lead working group with advisors</p>
<p>3.5</p>	<p>Wish of a Life Time Chartwell</p>	<p>-Cathy informed group of organization wish of a life time Canada. Similar to children’s wish foundation but for older adults near the end of life.</p>	<p>-Ashley will ask Julie Stewart from chartwell for write up to feature in next newsletter.</p>

	<p>Round Table</p>	<p>-Bonnie inquired about HMMS staff having a shadow day in the units at KCC.</p> <p>-Bonnie discussed how she is provided written results for clinic appointments with her lab values, normal values and signs and symptoms to watch for. Home Hemo and PD units give these to patients.</p> <p>-would like to see expanded to gen neph, MCKC and transplant clinics</p>	<p>April to arrange meeting with HMMS and Bonnie.</p>
<p>5.2</p>	<p>Next Meeting Date</p> <p><b>Meeting dates and locations 2019/2020</b></p>	<p><b>Tuesday January 14, 2020 at University Hospital Room B3-240</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>Tuesday January 14, 2020 at University Hospital Room B3-240        Wednesday February 12, 2020 at University Hospital Room B3-240</p> <p>Tuesday March 10, 2020 at Victoria Hospital Room B2-124        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>	