


**RENAL PATIENT AND FAMILY ADVISORY COUNCIL**  
**Virtual WebEx MEETING MINUTES**  
**Tuesday, November 10, 2020**  
**4:00pm to 6:30pm**

**In Attendance:** Betty Clinton (Chair), Kathleen Anderson (Co-Chair), April Mullen (Director), Lesley Pringle (Manager), Bonnie Field, John Wittenveen, Deb Beaupre, Pam Ireland, Doris Kannon, Cathy DuVal


**Minutes:** Crystal-Ann Roy

**Guest Speaker(s):**

**Regrets/Absent:** Dr Faisal Rehman (Physician), Kathy Austin

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.0	<b>Welcome, Approval of Minutes</b>	October 7 <sup>th</sup> 2020 minutes approved.   2020 10 07 MINUTES RPFAC.pdf  Welcome – Ashley Papathanassiou, new Renal PFAC Facilitator	<b>Minutes were lost. Send Crystal-Ann any corrections.</b>

<p>3.0</p>	<p><b>Task Group Reports</b></p> <p>1. <i>Communications &amp; Feedback Task Group</i></p> <p>3.1.1</p> <p>3.1.2</p> <p>3.1.3</p>	<p><u>Satellite Visits:</u> Deferred</p> <p>The VP of Cancer Services, Tom McHugh, is currently touring the satellites. Yesterday he was at Hanover, Goderich and Owen Sound. Later this month he will visit Woodstock. He spoke to patients in Owen Sound in regards to their patient experience and they seemed very happy.</p> <p><u>Home Rates Improvement Action Pan/Transitional Unit:</u> Deferred</p> <p><u>Kidney Foundation Peer Support:</u></p> <p>Kathleen and April met with Craig Lindsay. He sent pamphlets to be distributed to the patients offering them the option for virtual and/or telephone support.</p> <p>Peer support: <a href="#">You Tube Video</a></p>	<p>If there is anything PFAC would like asked, let April know.</p> <p>April will promote to staff as well as distribute pamphlets and info to the program (add link to renal website).</p> <p>Kathleen to follow-up on information to be added to the Kidney Kronicle.</p>
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	<p>3.1.4</p> <p>2. PFAC Newsletter</p>	<p><u>Patient Feedback Boxes:</u></p> <p>Not working at the moment.</p> <p>The next newsletter is expected to go out in December. Bonnie agreed to continue collecting information to be included. Due to cost the target should be 4 pages. Inserts can be printed in-house and added if necessary.</p> <p>Not all members received a copy of the previous newsletter:</p>  <p>Version 2 Kidney Kronical October 20.</p> <p>Concerns with emailing a copy of the newsletter to patients:</p> <ul style="list-style-type: none"> <li>- Privacy of patients.</li> <li>- Not sharing email addresses when sending out (build a list and Bcc to hide addresses). What if you forget to Bcc?</li> <li>- Who will input email addresses? There are approx. 1400 clinic patients.</li> <li>- Specific consent required? How to get it?</li> </ul> <p>Important to reach as many patients as possible. If emails were sent then pre-dialysis patients could also be added to the list.</p> <p>Clinic patients are only being seen over the phone so it is important that they somehow receive the information.</p> <p>If e-mailing patients is established then it can be used for other communication as well – COVID news, reminders etc....</p>	<p>To be added to parking lot items until after Covid.</p> <p>Bonnie is to collect information and forward to Crystal-Ann for formatting and printing.</p> <p>Lesley to look at email from Bonnie.</p> <p>Ashley will look into LHSC regulations and discuss options with clinics.</p>
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<p>3. Recruitment &amp; Orientation</p>	<p>Lesley has a call in with Patient Experience to obtain information concerning the onboarding process if someone would like to join PFAC.        Lesley and Ashley have spoken with someone who seems interested.</p>	<p>Lesley/Ashley to connect in a couple weeks to ensure things are progressing.</p>
<p>4. Transportation Update</p>		
<p>3.4.1</p>	<p><u>Local:</u></p> <p>Selena will be joining the December meeting to present a report on the patient assistance fund and the challenges the patients are experiencing. The report was forwarded to the VP and the ORN who then forwarded it to their analysts. Transportation concerns were included.        ALU had a Covid positive patient who encountered issues with transportation due to the fact that the taxi companies refused to drive her and Voyageur would have cost \$270.00. The Health Unit was able to make arrangements until she was cleared at no cost to the patient or the program.        Worthwhile to refresh the transportation list to see who will transport Covid patients? May not be as big an issue now that they have proper PPE.        Ashley is waiting for information/costs in regards to a program, Seniors for Seniors, which may aid with transportation issues.</p>	<p>??? refresh transportation list.</p> <p>Ashley to let Social Workers know and pass on info to Crystal-Ann for the Kidney Kronicle if useful.</p>
<p>3.4.2</p>	<p><u>Provincial:</u></p> <p>Nothing to report.</p>	

<p>5. Other Committee Reports</p> <p>3.5.1</p> <p>3.5.2</p> <p>3.5.3</p> <p>3.5.4</p>	<p><u>Renal Joint Health &amp; Safety:</u></p> <p>Nothing to report.</p> <p><u>Renal Infection Control:</u></p> <p>Nothing to report.</p> <p><u>KCC CQI:</u></p> <p>There is not likely to be a meeting before the new year.        UH started back this week and will be looking to recruit a PFAC representative asap.</p> <p><u>Renal Executive:</u></p> <p>On Sept 23<sup>rd</sup> the ORN discussed programs in the GTA and home dialysis in LTC. They are not going any further with it at the moment.        There is research being conducted with a small number of tech-savvy patients who are trying virtual clinics.        It was suggested that a thank-you from PFAC go out to Dr. Rehman for the \$10,000 he donated from the Showdown this year.</p>	<p>Lesley/Ashley discuss with Nissa and Jacquie Crandall how ALU is doing – is there a gap? Do they need a patient voice?</p> <p>April will pass on the address to Betty who will send a thank-you card on behalf of PFAC.</p>
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	<p>3.5.5</p> <p>3.5.6</p>	<p><b><u>Renal Nursing Professional Practice:</u></b></p> <p>Bonnie attended the meeting in September as an AdHoc member because they were discussing clinical bloodwork sheets. They are trying to have them accessible for MCKC patients however the form is quite complicated. There is a meeting tomorrow and it will be back on the agenda.</p> <p><b><u>Renal Provincial PFAC Updates:</u></b></p> <p>There was a meeting at the end of October where there was an update on converting to Ontario Health and an overview of the programs – they will continue “as is”.</p> <p>Dr Blake presented an update on Covid. He said that it hasn’t really affected dialysis patients so far and he feels that they are protected. If a dialysis patient contracts Covid there is a 25% chance it is fatal.</p> <p>There is an increase in patients wanting home hemo.</p> <p>They changed the term for PFAC advisors to 3 years and will extend by 1 year if needed.</p>	
<p>4.0</p>	<p><b>Open Discussion</b></p> <p>1. PFAC representative to join the PEAC</p> <p>2. <i>Kidney Kronicle</i></p>	<p>The PEAC is looking for a PFAC representative to join their committee to facilitate better communication between them as well as provide reports. Kathleen is already on the committee and it was suggested that she give updates as opposed to adding someone else.</p> <p>May not be realistic to add someone when we are already struggling to recruit and it would mean adding another monthly meeting.</p> <p>Already covered – 3.2</p>	<p>Kathleen will report to the PFAC committee over the next couple of months - someone may become interested.</p>

<p><i>3. Agenda</i></p>	<p>Lesley suggested everyone look at the agenda. Send items to parking lot?        Change template? Add/remove?</p>	<p>Send any suggestions to remove or add to Crystal-Ann. Crystal-Ann will prepare a new agenda template based on these suggestions.</p>
<p><i>4. Patient Portal</i></p>	<p>The Patient Portal was discussed at the last meeting however was not looked into (no reminder - minutes were lost). The portal would allow patients to access their bloodwork information. April to pilot?</p>	<p>April will set up 30 min meeting with Kathleen to discuss.</p>
<p><i>5. Round Table</i></p>	<p>Try a different platform for next meeting – zoom???? What is allowed?</p> <p>The bulletin boards at UH are messy. Ideally, they would have one like Westmount so that all of the information is in one area as opposed to all over the waiting area.</p> <p>The new Operations Manager, Jamal El Firikh, starts on November 30<sup>th</sup>. One of his responsibilities will be the website updates.</p> <p>Renal diet poster – pocket size?</p>	<p>????</p> <p>Add to parking lot until things are back to normal.</p> <p>Lesley to invite him to the PFAC meeting in January.</p> <p>????</p>

		<p>April presented an urgent issue concerning a Baxter product. A PD nurse flagged an issue she was having with Baxter PD transfer sets (the piece that attaches to the PD catheter with a twist cap to allow connection to the PD bag for inflow and outflow).        Baxter was informed of the issue - they claimed to be aware and would send new product.        Thursday, there was a teleconference for leadership from all Regional Renal programs – 9 programs identified they were experiencing similar issues, dating back to September.        The issue seems to be related to solution flow and leaking under the cap caused by a manufacturer product change in April.        Recommendations are that there will not be routine transfer set changes at this time, consider alternative product (supply may become an issue), avoid using new transfer sets.        Primary complaint by patients is the need to travel to have it replaced so we will be sending staff to them.        A letter will be going out to patients advising them of the issue and listing the concerns to look out for.        LHSC was very helpful with the investigation thanks to documenting lot numbers. 8 lot numbers have been identified as being affected.</p> <p>The Terms of Reference state that the Chair and the Vice-Chair must be a “patient or family representative”. Doris does not feel that she fits into either of these categories and wonders if the wording should be changed.        Wording changed?        Also, should there be a timeframe for being on the committee when there are already recruitment issues (provincial is 3 years)?        What is the ideal number for committee members?</p>	<p>On behalf of PFAC, Doris will send a thank-you card to the nurse (Sue Simpson) who first made the program aware and may have saved lives as well as the team for being diligent with documenting information.</p> <p>Give thought - will be discussed further at December meeting.</p>
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5.0	<b>Housekeeping</b>	<p><b>Next Meeting Date:</b> Wednesday, December 9<sup>th</sup>, 2020 @ 4:00pm.</p> <p><b>*Wear your Christmas sweater!</b></p>	<p>Crystal-Ann to send out new meeting reminders with 4pm start time.</p>