



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



**In Attendance:** John Witteveen, , Janice McCallum, Don Smith, Jim Harrington, Angela Andrews, Cathy DuVal, Betty Clinton, Michelle Ivanouski, Johanna Lane,

**Regrets/Absent:** , Nikki Anderson, Emma Klotz, Dr. Rehman, Anne Hutchison, Nancy Wilder, Bonnie Field (Chair), April Mullen, Kathy Austin, Minoo Hatami, Bob Barnicoat, Deb Beaupre

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of February 13, 2018 approved.	
1.2	Welcome to new members	PFAC has on boarded 3 new members, welcome to Johanna Lane, patient, Minoo Hatami, family member and Kathy Austin, RN from Westmount dialysis unit	
1.3	Additions to the Agenda	4.3 Report from Leah Getchell-Angela 4.4 Patient Portal-Janice	
2. 1	ORP 3 PFAC Consultation	ORP (Ontario Renal Plan) 1 centred around standardizing funding across all regions, growing home therapies and improving surgical wait times for vascular access ORP 2 (2015-19) Centres around person centred care, and improving the transplant workup process. Across all regions each PFAC is being consulted for ORP 3, and their	 Invitation to local PFACs for ORP3.pdf -We can revisit our group

		<p>thoughts on how to improve kidney care, as well as staff and physician groups, Trillium gift of life, the Kidney Foundation and various stakeholders.</p> <p>-The ORN will be coming to LHSC on April 18 (to both KCC and UH) to consult with patients and families. PFAC members are invited to join also</p> <p>-PFAC has been asked to answer the following 3 questions as a group, and Janice facilitated a conversation with the group to generate answers to present to the ORN.</p> <p>1. If you could use 3 ways to describe kidney care right now, how would you describe it and why? (Example: Caring, Compassionate Care, Confusing, Overwhelming)</p> <p>2. How would you describe excellent kidney care? If you could choose only 3 things necessary for this excellent care, what would they be and why? (Example: Compassion, good communication, etc.)</p> <p>3. If you could make 3 improvements to kidney care, what would they be and why?</p>	<p>answers at the next PFAC meetings also</p> <p>-Janice has taken the current list of answers for Joanne to type up</p>
3.0	Task Group Reports		
3.1	Communications & Feedback Task Group	<p>-satellite visits to Hanover and Owen Sound will be planned sometime in May to avoid bad weather, will do both in one day</p>	
3.2	Patient Education Task Group	<p>-Bonnie would like this group to start work on a PFAC Patient Journal where patients can record appointments, blood work, etc. relating to their renal health</p>	

3.3	Patient Transportation Task Group	<p>-PFAC has received a response to our letter from Chris Murphy at LTC, inviting us to the offices on Highbury to look at their new computer system</p> <p>-a patient from UH has asked to join the group, she is actively using paratransit, and experiences many issues, so would like to be part of the transport group as an associate member</p> <p>-a pre meeting has been set up for March 22 with the task group over at UH to discuss our plan for the meeting, a tentative date to visit the LTC will be April 25<sup>th</sup>.</p> <p>-Bonnie received a reply from the letter sent to Mike McCormick, the Provincial ORN PFAC chair, regarding transportation</p> <p>-currently the provincial PFAC is not working on any transportation related projects; Mike replied they have not heard of transport issues from any other regions.</p> <p>-Bonnie sent him a reply with some of the info we collected from the patient transportation survey, and info about the LTC meetings and comments from satellite patients</p>	
3.4	Newsletter	<p>-went out last week of February, next edition will go out in late May</p> <p>-next newsletter will have details of patient experience week, and some peer support info, and info about coverage for the pneumovax vaccine for renal patients</p> <p>-if there is any content you would like to add, please contact Angela</p>	
3.5	Patient Experience	<p>-there is a Patient Experience Forum on <b>Tuesday March 20, 2018 1:30 pm – 3:00 pm OR Wednesday March 21, 2018 4:30 pm – 6:00 pm</b></p> <p><b>Location (for both dates): Room C3-301A&amp;B, Victoria Hospital</b></p> <p>-see attached agenda for parking and location instructions</p>	 <p>Pt Experience        Advisor Forum Agend</p>

3.6	<p>Other Committee Reports: Parkwood Project</p> <p>Emergency preparedness</p>	<p>-Parkwood is up and running, and going well, Betty attended the ribbon cutting ceremony</p> <p>-there will be an open house on <b>Tuesday, March 20 between 2 and 4 pm at the Parkwood Institute Main Building 5BW Room B5 – 151</b></p> <p>-the staff in the renal program are currently being educated about the plan, huge thanks to Anne for her contribution to the committee and plan</p> <p>-the info has been added to the renal patient web</p>	 <p>Poster - Open House Dialysis Service at Pa</p> <p><b>Let Angela know by tomorrow if you would like to attend and she will arrange parking passes</b></p>
4.0	<p>Open Discussion</p> <p>4.1 Patient Experience Week</p> <p>4.2 World Kidney Day</p>	<p>-Patient Experience Week is June 18 to 22<sup>nd</sup></p> <p>-Don is participating on the pt. exp. Committee to plan the event</p> <p>-there are events planned all week at Victoria Hospital, including LRCP and Children’s hospital, as well as UH and KCC</p> <p>-a draft of the event for the week is attached, Don will be looking for PFAC volunteers to attend at the KCC location, he will e-mail a schedule and be looking for volunteers</p> <p>-on the last day of the event, there are plans to have an LHSC advisor appreciation day, where advisors can attend and network with other advisors</p> <p>-the displays for World Kidney Day went well, Riz from the Kidney Foundation was present at the YMCA and Movati gyms with Betty and Don, Anne and Angela were located at VH</p> <p>-great feedback on the pens that were given to patients and staff</p> <p>-there will be a photo of the display from VH in the Page Magazine, Angela will forward when available.</p>	 <p>Draft Patient Experience Week Sch</p>

4.3	Report from Leah Getchell	<p>-Have been working with patient partner Jim O'Donnell on running interviews and focus groups to determine a new CKD &amp; Diabetes care program to be trialed locally (Dr. Clements involved in this, Don and Janice saw the presentation of her work recently, and have recommended it to PFAC that she present her work at the PFAC)</p> <p>-Dr. Garg's research program around doing innovative clinical trials for in-center hemo patients is gearing up. If you are interested in joining the research team, get in touch with Leah Getchell</p> <p>-George Goodlet continues to participate on the steering committee for Dr. Jain's PD 'CONNECT Trial'</p> <p>-Transplant Ambassador Program is gearing up to launch April 1st, will be doing a 'test run' in the MCKC clinic with plans to roll out to the remaining units at Westmount, then the ALU and UH sites.</p> <p>-March is World Kidney Month; March 8th is both International Kidney &amp; Women's day! Follow the conversation during March on Twitter: @cansolveckd or on Facebook: Can-SOLVE CKD Network</p>	<p>-Angela will touch base with Dr. Clements to see if she would be interested in presenting her research to the PFAC at the May meeting</p>
4.4	Patient Portal	<p>-Janice mentioned that patients have been expressing interest for some time in a Patient Portal, where they can have access to their charts and records on line, as well as support from other patients and families</p> <p>-LRCP and the St. Joseph's Breast Care program are trialing a patient portal that may be running as soon as April 2018, in conjunction with Hamilton Health Sciences Centre.</p> <p>-if the trial goes well, they may spread it more broadly in 2019 where renal can join in</p>	
5.0	Housekeeping		
5.1	Summary of Action Items		
5.2	Next Meeting Date	Tuesday April 10, 2018 at 5:00pm at <b>Victoria Hospital room B2-124</b>	

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