

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL  
MEETING MINUTES  
Tuesday February 14, 2017  
5:00pm to 7:30pm  
Kidney Foundation Office**

**In Attendance:** Fred McInnis (Chair), Paul Dixon (Vice Chair), Philip Varughese, Betty Clinton, Deb Bezaire, Angela Andrews, Bonnie Field, Don Smith, Janice McCallum

**Guests:** Leah Getchell, Dr. Rehman, Cathy DuVal, Nancy Wilder, Robert Barnicoat, Viengkham Chanthalan Sy, Jarrin Penny, John Witteveen, Emma Klotz

**Regrets/Absent:** Dr. McIntyre, Deb Beaupre, George Goodlet, Nikki Anderson, Michele Ivanouski, Anne Hutchison, Mike Smith

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1 1.2 1.3	Welcome, Approval of Minutes Additions to the Agenda Opening Patient Story	Minutes of December 13, 2016 approved as distributed. Welcome new members John Witteveen and Emma Klotz Bonnie shared a personal health story about a potential medication error that happened while she was an inpatient and how this affected her.	
2.1	Guest: Leah Getchell from the Institute of Clinical Evaluative Sciences (ICES) and Kidney Clinical Research Unit (KCRU)	ICES is a not-for-profit research group that encompasses a community of research and leads cutting-edge studies that evaluate health care delivery and outcomes. ICES researchers access a vast and secure array of Ontario's health-related data, including population-based health surveys, anonymous patient records, as well as clinical and administrative databases. ICES Western is a branch of the national group, and is run out of Victoria Hospital The Lilibeth Caberto Kidney Clinical Research Unit (KCRU) is a 4,000 square-foot facility located at Victoria Hospital, <a href="http://www.lhsc.on.ca">London Health Sciences Centre</a> (LHSC). The KCRU is dedicated to clinical research in the areas of kidney health, kidney disease and treatments of dialysis and kidney transplantation.  Leah discussed what research is, why we do it and where the funds come from. She also talked about SPOR (the Strategy for Patient Oriented Research) Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves	Visit: <a href="http://www.cansolveckd.ca">www.cansolveckd.ca</a> for more info  <a href="http://www.cihr-irsc.gc.ca/e/41204.html">www.cihr-irsc.gc.ca/e/41204.html</a>    Patint-Oriented Research_PFAC.pptx    can-solve-ckd-overview_PFAC.pptx

2.2	ORN Update	<p>patient outcomes.</p> <p>Leah also talked about patient oriented research and CanSOLVE (see website and slides), and lastly the group discussed the best ways for Leah to recruit patients and families to join research studies.</p> <p>The ORN sponsors the Human Touch Awards yearly, this year both Deb Bezaire, Manager and Nancy Woodcock, Dietitian have been nominated by the LHSC Renal Program. Good Luck Nancy and Deb!</p> <p>Deb Bezaire is retiring in May, April Mullen, previous LRCP program manager and Nursing Director of Tillsonburg hospital will be filling her position</p> <p>The joint review of the Kidney Foundation Peer Support Program by the KF and ORN has been completed, they will be sending posters and brochures of the review results soon</p> <p>The success of the ORN “Save my Vein” initiative is being evaluated by the ORN, they will be looking for patient feedback on the initiative</p> <p>The ORN is doing a current state analysis of the multidisciplinary kidney care clinics (also known as CKD clinics). They are looking at the variability of the different programs across the province and looking at trying to streamline the clinics following best practice guidelines.</p>	 <p>Roles for patients in research.pdf</p>
3.0	Task Group Reports		
3.1	Patient Resource Task Group	<ul style="list-style-type: none"> <li>-the task group met Feb 1 to look at different educational resources for the resource centres</li> <li>-we have one resource centre set up so far in the CKD waiting room at KCC, there are two more on order for both UH and VH</li> <li>-there is a comments box and poster asking for users to comment on the resources available, and to make requests for more info</li> <li>-if PFAC members find info they would like to be displayed, please bring it to the group</li> <li>-we discussed creating some kind of booklet for patients to write important medical info, Physician’s</li> </ul>	

		<p>names, etc.</p> <ul style="list-style-type: none"> <li>-we discussed having business cards of allied health team members on the resource centre. There is concern about doing this as every patient has a specific allied health team member assigned to them (usually based on dialysis modality or location) and if all the cards are out there patients may not know which allied health team member is assigned to them, and the staff will be getting a large number of misdirected calls.</li> <li>-the group agreed that although patients might not know who is assigned to them, they know to ask their nurse who will direct the right team member to them</li> </ul>	
3.2	Communications and Patient Feedback Task Group	<ul style="list-style-type: none"> <li>-the group discussed possibly hosting a Kidney patient education day as a way of making contact with home dialysis patients, and CKD patients who we have little contact with. The event would involve bringing together several members of the allied health team (dietitians, social workers, nurse case managers, etc.) as well as pfac, and possibly the Kidney Foundation and providing info on topics such as dialysis modalities, dialysis access (perm cath and fistulas), diet, medications etc.</li> <li>-Deb suggested that before planning the event we survey patients to see if this is something they would be interested in, so the group decided to create an online “survey monkey” and advertise it in the newsletter as well as a handout with the mail outs to direct people to the survey</li> <li>-Deb also suggested we survey the pfac members to see if all are interested in an event like this by using a survey monkey so we can have a confidential ballot</li> <li>-Deb would also like the PFAC to submit a proposal about the event including info about cost, locations, topics, speakers, etc. to her and Janice before starting to plan the event. Angela will set up a task group meeting to discuss these details.</li> </ul>	
3.3	Patient Transportation Task Group	<ul style="list-style-type: none"> <li>-at the time of the meeting the group was awaiting confirmation from Chris Murphy about a meeting date with LTC (meeting date has been set for Wednesday March 8 at 1:00pm in Room 2111 at KCC)</li> </ul>	
3.4	Newsletter	<ul style="list-style-type: none"> <li>-The next newsletter will go out in March, please submit anything that you would like in the letter to Angela soon. Val Cameron, one of the charge nurses in dialysis at UH has agreed to be interviewed via email; Don and Paul will work together on this.</li> </ul>	

<p>3.5</p>	<p>Recruitment &amp; Orientation Task Group</p>	<p>-there was a discussion on membership, 2 new members have been on boarded, Emma and John        -currently there are 7 other patients/family members interested in joining the council, however the size of our meeting room at the KF limits us to the size of pfac group that we can have        -Fred suggested that we contact the interested individuals and thank them for their interest, but let them know that we are not looking for members at the moment, and that we will keep their name on file for the future. Angela will contact them.        -a survey will go out to the new members who attended the renal pfac orientation soon about their experience with the orientation in August</p>	
<p>3.6</p>	<p>Patient Experience Coordinating Committee (PECC)</p>	<p>-During the January Patient Experience Coordinating Committee, members were introduced to the concept/purpose of Quality Improvement Plans (QIP's). Each year, Health Quality Ontario asks organizations to focus on a handful of key issues that are priorities in Ontario, such as ensuring patients have timely access to care, and ensuring patients are satisfied with the care they have received. Health care organizations are legally required to submit a QIP to Health Quality Ontario each year by April 1<sup>st</sup>. The PECC group participated in an interactive exercise where they were asked to prioritize 7 out of 10 indicators they felt LHSC should include in the development of their Quality Improvement Plan (QIP). The group rated their top 7 choices of importance from 1 (very important &amp; first choice) to 7 (important but last choice). Their choices will be included with the broader working groups and hospital leadership will then identify which 7 indicators will be used in the 2017/18 Quality Improvement Plan. Deb and Bonnie will share the 7 indicators with PFAC once they have been confirmed.</p>	
<p>4.0</p>	<p>Open Discussion</p>		
<p>4.1</p>	<p>Hip Chat</p>	<p>-the LHSC sanctioned Cisco Jabber alternative to HipChat is not active yet, Fred is keen on providing this chat group availability to home dialysis patients, so this topic will be deferred to the next meeting</p>	
<p>4.2</p>	<p>A discussion on engaging home dialysis population</p>	<p>See discussion under 3.2, patient education day</p>	
<p>4.3</p>	<p>PFAC Membership</p>	<p>-see section 3.5</p>	

4.4	Meeting Cancellations	-Betty requested that when a PFAC meeting is cancelled we make the decision by noon on the day of the meeting so that individuals who have to travel to get to meetings can make arrangements, the group agreed.	
5.0	Housekeeping		
5.1	Next Meeting Date	Tuesday March 14, 2017 5:00pm to 7:30pm, <b>Kidney Foundation Office</b>	