

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL  
MEETING MINUTES  
Tuesday May 8, 2018  
5:00pm to 7:30pm  
Victoria Hospital Room B2-124**

**In Attendance:** Don Smith, Jim Harrington, Angela Andrews, Cathy DuVal, Betty Clinton, Johanna Lane, Anne Hutchison, Bonnie Field (Chair), April Mullen, Kathy Austin, Minoo Hatami, Guest: Don Bester

**Guests:** Dr. Kristin Clemens and Rebecca Abreu

**Regrets/Absent:** Emma Klotz, Dr. Rehman, , Bob Barnicoat, Deb Beaupre, John Witteveen, Janice McCallum, Nancy Wilder, Michelle Ivanouski

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes from April 10, 2018 approved	
1.2	Member update	-Nikki Anderson has resigned from the council to work on her health -Bob Barnicoat will complete his service at the end of June -Welcome to Sara Shrubsall, a potential family member is observing the meeting today	
1.3	Additions to the Agenda	4.5 PFAC Evaluation	

2.1	Presentation	<p>Patient Centred Diabetes and Chronic Kidney Disease Research presented by Dr. Kristin Clemens and Patient participant Jim O'Donnell</p> <ul style="list-style-type: none"><li>-the goal of the study was to engage patients to develop better diabetes care</li><li>-the numbers of patients with diabetes and kidney disease is increasing, as well as the rates of patients with more than one major chronic illness, therefore more requirements for diabetes support and screening are arising</li><li>-interviews were held with patients (including past PFAC member Paul Dixon) and they shared their stories and the impact that CKD and diabetes had on their life and the health care experiences and challenges</li><li>-findings indicated that there are "silos" for medical care, where each disease is looked after by a separate specialist, and there is often suboptimal communication between specialties and patients felt like "go-between" for each specialist and has a need to advocate for self</li><li>-this led the team to create 4 top strategies to help patients deal with their illness:<ul style="list-style-type: none"><li>• Care coordination:<ul style="list-style-type: none"><li>○ Bring diabetes care to patients, integrate with other aspects of care</li></ul></li><li>• Dialysis-based screening<ul style="list-style-type: none"><li>○ Foot screening in the dialysis unit</li></ul></li><li>• Self-management<ul style="list-style-type: none"><li>○ Technologies to help patients track blood sugars, medications, appointments</li></ul></li><li>• Education<ul style="list-style-type: none"><li>○ Importance of managing diabetes and complications</li></ul></li></ul></li></ul> <p>-2 top strategies were narrowed in on, care coordination for patients, and dialysis based screening and will require further study to evaluate the effectiveness of programs like the</p> <p>-the suggestion of introducing a certified diabetes educator to the renal program was made based on the findings</p>	
-----	--------------	---	--

2.2	Presentation	<p>-Jim O'Donnell shared his experience as a patient receiving conflicting information around diets and medications from each specialty area that landed him in hospital several times. He also discussed his wish that when he was told that he had diabetes 40 years previously, that a health care provider would have told him the complications of diabetes so we would have controlled the diabetes better.</p> <p>-Jim's experience emphasized the importance of coordinating care for people with multiple diseases</p> <p>-Rebecca Abreu from the Patient Experience Dept. visited the group to discuss Advisor website/portal work that is underway</p> <p>-previously work had been started on a site that would allow LHSC to transfer information to advisors, but is hearing from advisors that they are looking for a place to feel connected to other advisors</p> <p>-referring to is as a website rather than portal since there is work underway to have a portal for all patients that would contain medical information, this website will have advisor information and allow advisors to connect with others, as well as a place for councils to share with each other and a drop box for councils to work on documents together</p>	
3.0	Task Group Reports		
3.1	Communications & Feedback Task Group	<p>-visit planned to Hanover and Owen Sound Satellite dialysis units for Thursday May 31, Anne, Betty, Don, Angela and Terri (coordinator for satellites) will attend the visit</p>	
3.2	Patient Education Task Group	<p>-Bonnie is doing some investigation for the group around the need for a patient journal, talking with clinic nurses and staff to determine if patients currently use something similar</p> <p>-A proposal was sent to the Westmount CQI about the possibility of them working with Education task group to create a list of community resources for patients, Anne mentioned that she had a list of community resources the</p>	

<p>3.3</p>	<p>Patient Transportation Task Group</p>	<p>LHIN (previously CCAC) had created, possibly we could build on this list. Don will ask his LHIN nurse about getting a list.          -Bonnie to attend the CQI meeting next week to discuss the proposal          -meeting held with LTC, April, Bonnie, Denise, Angela, Selena attended          -good discussion with group however many of the issues that the transport group mentioned have not been resolved          -the group did commit to LTC to create a process for the dialysis units to call the paratransit office as early as possible if a patient is going to be late to catch their bus at the end of dialysis, to try to get a bus rerouted as soon as possible          -the task group is going to meet again to discuss the meeting and outcomes          -Bonnie is going to write to the APTSAC advisory committee to ask about adjusting the start time of all buses, including paratransit to be 7am on stat holidays</p>	
<p>3.4</p>	<p>Newsletter</p>	<p>-will go out June 1<sup>st</sup> to advertise the Patient Experience week. Other topics include the Kidney Foundation peer support program and the emergency preparedness work.          -Sara requested that some of the newsletters be brought down to the PMDU where pediatric nephrology patients are seen so they can see the letter also</p>	
<p>3.5</p>	<p>Patient Experience Week</p>	<p>-week is June 18-22 to celebrate the relationship between patients/family and caregivers          -Don and Rebecca presented a schedule of the advisor volunteer hours that they need for the June 18 to 22 Patient experience week at KCC          -there will be patient advisors at all sites greeting staff and promoting Pt experience, as well as recruiting for new advisors          -at KCC there will be pt. advisor greeters in the main entrance way to greet staff and patients as they arrive for dialysis</p>	<p>-Angela will send out schedule for volunteers, we will need about 4 volunteers</p>

3.6	<p>Other Committee Reports: Parkwood Project</p> <p>Emergency preparedness</p>	<p>-Rebecca also asked for each council to provide several examples of the greatest achievements to highlight our areas of success, this will be posted on the display with the advisors</p> <p>-Parkwood running smoothly</p> <p>-April and Betty along with several other involved in the proof of concept project will be presenting June 11 to 13 in Baltimore at the <i>International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities</i> about their work on the project. Betty and April will report at the June 19 planning meeting</p> <p>-Anne is finalizing the general pamphlet for patients for the emergency preparedness that will go out with the newsletter</p> <p>-the group also noticed that the contact person on the pamphlet is not correct, Angela will investigate who the right person should be</p>	
4.0 4.1	<p>Open Discussion</p> <p>Planning meeting</p>	<p>-We will be changing our June meeting to June 19 at 5:00pm so that we can have a planning session for our next PFAC year starting in September</p>	
4.2	<p>Review of PFAC ORP 3 Consultation</p>	<p>-the ORP 3 PFAC consultation work is due May 31, so PFAC made a few finishing touches to the previous work that was completed- an updated copy will be attached</p>	
4.3	<p>Leadership interview questions</p>	<p>-April explained the leadership interview questions were sent to advisors for review since there are currently not enough advisors to attend every interview, so the creators wanted several questions that would focus on person centred care to capture the interviewee's knowledge or thoughts about the patient experience.</p> <p>-Pfac noted that the 4 main principles of person centred care were missing from the questions- communication/information sharing, dignity/respect,</p>	

4.4	ORN Patient and Family Engagement Dashboard	<p>that care is coordinated/comprehensive, collaboration/empowerment</p> <ul style="list-style-type: none"> <li>-April will submit the suggestions</li> <li>-ORN created an online dashboard to display the patient engagement plans for all Renal centres across Ontario</li> <li>-the dashboard is attached to the minutes</li> <li>-it's a good way to translate knowledge, and get new ideas for what our PFAC would like to work on</li> </ul>	
4.5	PFAC Evaluation	<ul style="list-style-type: none"> <li>-Angela handed out a PFAC evaluation form to everyone (staff and patients/family)</li> <li>-it's a requirement to meet the standards of accreditation that the program evaluates their person centred care/patient experience initiatives</li> <li>-more than that, it's important for the program to know that we are meeting your needs as advisors also</li> <li>-the evaluation will be used in the planning meeting in June to create new ideas for PFAC to work on next year</li> </ul>	
5.0	Housekeeping		
5.1	Summary of Action Items		
5.2	Next Meeting Date	<b>Tuesday June 19, 2018 at 5:00pm at Victoria Hospital room B2-116</b>	