



**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday November 14, 2017
5:00pm to 7:30pm
Victoria Hospital, Room B2-116**



In Attendance: Bonnie Field (Chair), Betty Clinton, Nancy Wilder, John Witteveen, April Mullen, Janice McCallum, Don Smith, Jim Harrington, , Angela Andrews

Guests: Dr. McIntyre, Cindy House and Ruth Skinner

Regrets/Absent: Dr. Rehman, Anne Hutchison, Cathy DuVal, George Goodlet, Bob Barnicoat, Michelle Ivanouski, Deb Beaupre



	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of October 10, 2017 approved.	
1.2	Welcome new Vice Chair	Welcome and congratulations to our new PFAC vice-chair, Don Smith	
1.3	Additions to the Agenda	-Accreditation Volunteer (4.7)	
1.4	Patient Story Telling		
2.1	Renal Community Photo Initiative Presentation	Dr. McIntyre, Cindy House and Ruth Skinner presented to the group some of the results from the Photo Initiative Study Background: Study the connection between dialysis patients and depression and get a better understanding of patients' lives outside	

		<p>their dialysis treatment.</p> <p>Results: very few pictures of dialysis itself but rather the journey to get to dialysis, patient viewed dialysis as their job so weren't going to take pictures of that. Very few negative, most hopeful and thoughtful pictures demonstrating vulnerabilities, support, honesty Themes: beauty, exploration, natural shots</p> <p>Next step is to decide how to share this work. Dr McIntyre is looking for comments and suggestions from the pfac on how they should display this art work.</p> <p>Angela has emailed an updated task list group to everyone.</p>	
3.0	Task Group Reports		
3.1	Patient Resource Task Group	<p>-the group decided to put this task group on hold for now, the resource kiosks have been created, and just need to be maintained</p> <p>-it was decided to create a new group called the Patient Education task group</p> <p>Discussion on location of display stands. At UH enough space, KCC a concern. Content includes Kidney foundation info</p>	<p>-Angela will ask Val, Coordinator at UH about placing kiosk in transplant clinic for awhile</p>
3.2	Communications and Patient Feedback Task Group		
	3.2.1 Satellite Visit Reports	<p>-reports attached</p> <p>-Angela reported on satellite visits done so far, Chatham, Tillsonburg and Woodstock</p> <p>-the main themes of issues in the satellite remain around transportation and the cost as well as fistula needles problems</p> <p>-Woodstock unit talked about when a code blue happens in their unit, and the feelings associated with this</p> <p>-Angela will send the reports along to Janice, and with approval on to</p>	<p> Renal PFAC Chatham Satellite Visit Report \</p> <p> Renal PFAC Tillsonburg Satellite V</p>

	<p>3.2.2 Patient Education Day Survey Results</p>	<p>the satellite units -next visit planned for Sarnia, possibly December. Angela will be looking for volunteers to attend.</p> <p>-Angela shared the results of the survey sent out to patients regarding a possible education/patient experience day for patients. -out of the 785 surveys handed out (home patients had a mail out, in-centre and satellite unit patients had it handed out to them in their dialysis unit), there were 211 replies (27%) -79 of the replies said yes they were interested (38%) and 127 of the replies said no, they were not interested (61%) -69 (37%) said yes they would watch over the internet, 115 (62%) said no they would not watch over the internet -although the majority of patients were not interested in attending a patient education day, they did however indicate several topics that they were interested in learning about, the new patient education task group will look into getting this info put onto the patient education resource kiosks in the waiting rooms as well as articles in the newsletter</p> <p>Feedback: Patients have been surveyed and resurveyed and need a break, when not at dialysis people don't want to drive in for education. Janice – great response.</p>	<p> Renal PFAC Woodstock Satellite v</p> <p> survey results.pdf</p>
3.3	Patient Transportation Task Group	<p>-Angela contacted Fred regarding a follow up letter for Paratransit. Fred commented that a follow up letter was not written as the group felt that the new telephone system for paratransit needed time to allow patients to experience it and see if it improved anything with the service</p>	<p>Don to draft a letter for Paratransit.</p>
3.4	Newsletter	<p>-Newsletter to go out end of November. The group asked Janice to do</p>	

<p>3.5</p>	<p>Recruitment & Orientation Task Group</p>	<p>an interview for the “get to know the program members” article. -Angela will send the final out to Jim for editing</p> <p>-at the moment there are 4 members who are taking a LOA, Angela will begin the process to recruit more members</p>	<p>Janice to submit to Angela her portion.</p> <p>Jim has offered to edit.</p>
<p>3.6</p>	<p>Patient Experience Coordinating Committee (PECC)</p>	<p>Committee met in October, new kick off with focus on PFAC and advisor implementation on all LHSC committees</p>	
<p>3.7</p>	<p>Other committee reports 3.7.1 TAP-April</p>	<p>-Philip has resigned as head of the TAP committee, for now Leah Getchell will be the lead until a new patient/family member recruited</p>	
	<p>3.7.2 Parkwood Project-Betty</p>	<p>Last meeting Oct 22nd the group is very engaged and progressing well. Construction starts Nov 20th. Grand opening planned for Feb 12th. Betty asked if there would be a celebration event - we will plan for this shortly after opening.</p>	
	<p>3.7.3 Emergency Preparedness-Anne</p>	<p>-Anne and Bonnie will meet this week to look at the content for the Emergency preparedness pamphlet and will run the content by the group via email for comments</p>	

4.0	Open Discussion		
4.1	Poster Presentation for Parkwood Project-April	Poster submitted and accepted to the Institute of Patient Family Centre Care where Betty, April and Julie Gilvesy will present. The focus of the poster is on patient and family engagement in quality improvement projects.	
4.2	Name vs. Number discussion	<p>-Angela had been asked at last meeting to poll PFAC members about their feelings on being called name vs number, of the 9 responses, 7 were for being called by name, 1 was neutral and 1 was for number</p> <p>-April reported privacy has no concern whether we use one versus the other as it's mixed reviews from patients. Medicine unit would prefer we both use the same system. Will get feedback from clinic staff and physicians and update at next meeting.</p>	
4.3	Fistula working group-April	<p>We implemented new fistula needles and on evaluation patient feedback was that the needles felt dull and painful, from staff they were not consistently using the safety device. Started a working group to review which a patient Mark Estacio attended. We completed a trial of a new longer beveled needle with Mark and immediately it was apparent the new needle was better. We have now changed all of the needles across the region to the new longer beveled needle. The intention of sharing this story is to show the power of patient engagement to effect change.</p>	
4.4	Nocturnal in-centred dialysis update-Janice		
4.5	Team Care Research-Don/Angela	-Angela has shared some info with the group from Dr. Kristen Clemens and Leah Getchell regarding a study called Team CARE, a Patient-	

<p>4.6 4.7</p>	<p>LAUNCH Manual Review-Angela Accreditation Volunteer</p>	<p>centered Diabetes Care Program for People with Advanced Chronic Kidney Disease and Diabetes, the info is attached, if you know of any patient or family member that would be interested in this study please forward the info along to them</p> <p>-Angela sent the manual out to the task group that reviewed the original manual, as well as the rest of the pfac for a review</p> <p>-Philip has resigned from the Accreditation committee; we are looking for a new volunteer to be on this committee. Betty and Don have volunteered to attend.</p>	<p> Appendix A_ Study Recruitment Informat</p> <p> Launch_together_v5 Daniela.pdf</p>
<p>5.0 5.1 5.2 5.3</p>	<p>Housekeeping Summary of Action Items Next Meeting Date Upcoming Events</p>	<p>Tuesday December 12, 2017 at 5:00pm in room</p> <p>Stories of Health and Illness, Thursday November 23 at 6:30pm, Wolf Performance Hall, Central Library on Dundas Street</p> <p>Door decorating contest at KCC- if interested in judging let Bonnie know.</p>	