


**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday May 9, 2017
5:00pm to 7:30pm
Kidney Foundation Office**







In Attendance: Fred McInnis (Chair), Paul Dixon (Vice Chair), Philip Varughese, Betty Clinton, , Angela Andrews, Bonnie Field, Don Smith, Janice McCallum, Nancy Wilder, Viengkham Chanthalan Sy, Jarrin Penny, John Witteveen, Michele Ivanouski, Deb Beaupre, Anne Hutchison, Deb Bezaire, Dr. Rehman, Bob Barnicoat


Guests: Eleanor Rivoire , Cindy House, Ruth Skinner

Regrets/Absent: Dr. McIntyre, Nikki Anderson, Mike Smith, Cathy DuVal, Emma Klotz, April Mullen, George Goodlet

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of April 11, 2017 approved as distributed.	
1.2	Additions to the Agenda		
2.1	Guest: Eleanor Corpus Sanchez International (CSI)	<ul style="list-style-type: none"> -CSI attended the meeting to consult with members of the PFAC regarding LHSC's new strategic plan that is being developed and that will commence in April 2018. -the strategy has not been updated in 10 years, the CEO is stepping down and a new CEO is being recruited, so it was time to develop a new strategy -2 questions were asked, what is going well and what is not going well. Pfac responded with several suggestions, including: <ul style="list-style-type: none"> -Communication between departments and different institutions could be improved -More money allocated towards discharge planning, towards patient transportation, parking , travel expenses and education follow up for renal patients -the suggestion of a patient portal where patients could access their records be available 	

2.2	Renal Community Photo Initiative- Cindy House, Research Assistant with the KCRU (Kidney Clinical Research Unit) and Ruth Skinner, PhD Candidate, UWO	<p>-standardization of training for staff</p> <p>-Cindy and Ruth discussed the Renal Photo Initiative that is being sponsored by Dr. McIntyre. The study involves dialysis patients taking photos of their daily lives on a variety of camera types. The study is designed to provide caregivers and the health care community with a better understanding of what it's like to live with kidney disease.</p>	 2017 05 09 Photo initiative announceme
3.0	Task Group Reports	<p>Fred requested that we schedule task group meetings to review the work plans from the task groups</p> <p>3.1 Patient Resource Task Group</p> <p>-the display stand at the VH site has been moved into the kitchen, Angela will place large sign on the door directing people to the info in the kitchen area. -Fred shared that the resource task group envisions a 5 year plan to create an interactive resource centre for patients and families that is more than a panel of pamphlets</p> <p>3.2 Communications and Patient Feedback Task Group</p> <p>-The official final copy of the dialysis unit visit report was sent out to Janice last week -Survey monkey link requesting feedback from patients on the possibility of holding a patient education day has been published in the newsletter, as well as flyers sent along to each home dialysis patient, and flyers posted in all the dialysis units. The survey close date is May 16; there have been a few responses, but not many.</p> <p>3.3 Patient Transportation Task Group</p> <p>-have not heard anything back from Chris Murphy from LTC as of yet. The group intends on sending a follow up letter to LTC with the hopes of a follow up meeting being booked -patients have had a number of complaints since the new computer system has gone into place at paratransit</p> <p>3.4 Newsletter</p> <p>-If you have any suggestions for articles for the next issue (August) please forward to Philip and</p>	-Angela will schedule meetings

<p>3.5 3.6</p>	<p>Recruitment & Orientation Task Group Patient Experience Coordinating Committee (PECC)</p>	<p>Angela. -Selena the social worker at UH is working on an article about emotional stress for renal patients and Val Cameron is working on an interview with the charge nurse also. -the group suggested having a vascular access nurse write an article about the importance of saving your veins and the damage that blood taking can cause</p> <p>There was a new member orientation on April 26th for Emma and John, Veing attended as well. Evaluations of the orientation have been sent to them.</p> <p>-nothing to report</p>	
<p>4.0 4.1 4.2</p>	<p>Open Discussion Emergency Preparedness- Anne Patient Declaration of Values</p>	<p>-Anne has been involved in the emergency preparedness committee (EPC) for the Renal program, She shared several documents for the pfac to review regarding the emergency preparedness manual and information for patients -Anne asked that the council review the items and we discuss at the next meeting -Anne also asked the advisors to think of ideas for the best way for patients to be communicated to if a disaster does happen, for example, suggest that all patients keep a transistor radio available in case of emergency, and that an “emergency line” phone number be given to patients to call in to the renal program and get a recorded message on what to do if there is a disaster</p> <p>-Angela shared that she will be sending out some draft documents on what the Patient Declaration of Values will look like. The committee is looking for feedback on both the design of the document, as well as the content.</p> <p>Drafts 1 and 2 were shown to the LRCP PFAC for feedback on design. The statements for these two documents are still incomplete as they continue to sift through the comments from the survey results.</p> <p>Draft 3 was created as a result of the feedback received from the LRCP PFAC</p> <p>Please have a look at the documents and think about what aspects of the design resonate most with you and</p>	<p>  2016 Patient Disaster Plan Template (1).pdf BCPRA emergency info cards.pdf</p> <p> emergencyprepare1.pdf</p> <p>  PDOV - 1.pdf PDOV - 2.pdf</p> <p> PDOV - 3.pdf</p>

<p>4.3</p>	<p>KCC CQI (Continuous Quality Improvement)</p>	<p>what you don't like. Please respond to Angela with your comments to be forwarded onto the committee.</p> <p>The three main purposes for creating the document include:</p> <ol style="list-style-type: none"> 1. We have a requirement under ECFAA (Excellent Care for All Act) to create the document; 2. It will be used for the purpose of informing patients and families of their rights when receiving health care services; and 3. It will be used to educate staff and physicians what matters most to patients and families. <p>-John attended the CQI meeting at KCC, the council is asking what kind of information that patients and families would like to see on the bulletin boards in the main hallway leading to the hemodialysis unit at KCC</p> <p>-travel information for dialysis and renal patients was suggested</p>	<p>-please let Angela or John know some suggestions to send on to the CQI</p>
<p>4.4</p>	<p>Connect Trial</p>	<p>-Angela shared information from the the KCRU (kidney clinical research unit) who are looking for current or previous (last 2 years) PD patients</p> <p>-the study involves giving ipads to PD patients to determine if using technology can improve in-home support for patients</p> <p>-please respond to info on attached poster if you are interested</p>	<p> connect trial.pdf</p>
<p>5.0</p>	<p>Housekeeping</p>		
<p>5.1</p>	<p>Next Meeting Date</p>	<p>Tuesday June 13, 2017 5:00pm to 7:30pm Kidney Foundation Office</p>	