

**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 |
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| 1   | Welcome, Approval of Minutes    | Fred welcomed everyone. Minutes of February 14, 2017 approved as distributed.  |                              |
| 1.2 | Additions to the Agenda         | 4.4 OHA Visits   |                              |
| 1.3 | Opening Patient Story           | Anne Hutchison shared a story about starting dialysis.   |                              |
| 2.1 | Guest: Carolyn Ingram<br>LAUNCH | <p>LAUNCH (Learning about You New to Chronic Hemodialysis) program. The program involves the development of consistent, comprehensive practices and education for people new to hemodialysis making decisions for their care such as dialysis choices, vascular access, transplant and self management.</p> <p>Other centres in Ontario have provided this care by having a designated 'new start chair' in hemodialysis units which focus on designated staff with specific goals for teaching and supporting patients new to hemodialysis. Our program will not be a designated space in one particular unit but will be a virtual chair which follows the patient through their CKD journey. Patient education will not be limited to the physical location of the patient; rather preceptors will be trained and able to respond to patient learning needs at all dialysis facilities as learning needs arise. For example, if the patient starts hemodialysis at the acute care centre and then within 2 weeks is transferred closer to home to the satellite hemodialysis unit there will be skilled and motivated staff in each unit to help the patient adjust to hemodialysis and assist with decisions regarding their care.</p> |                              |

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|                            |  | <p>The whole idea is the content will be patient driven, in 20 min sections. Patients will have a listing of the titles of the sections and they will get to choose what is most important to them to learn.</p> <p>There will be nurses from each unit, including satellites that will be spending March 23 on a day of education, as well as armed with back up support, (me) to deliver the content. The spirit is to be patient centred, with the RNs armed with info re: health literacy, and appreciative of the fact patients need evidence based education in order to make good decisions for themselves. We intend to include the lab sheet, rejigged for HD that the patients worked on for pre-dialysis.</p> <p>The topics include infection, dialysis access, HHD, PD transplant including living related, sex. Social supports. The content is not necessarily strictly our manual, but also include some video snippets, the KF manuals, diet, foot care, and activity. The idea being that this would replace the 15 something pamphlets that we currently give out.</p> <p>Carolyn asked the council to review the education material. Fred suggested that a small task group be comprised to review material and grade the content. Nancy and Deb B. will be sharing their stories about starting dialysis.</p> | <p>PFAC task group to review education material.</p>              |
| <p>3.0<br/>3.1<br/>3.2</p> | <p>Task Group Reports<br/>         Patient Resource Task Group<br/>         Communications and Patient Feedback Task Group</p> | <p>Currently we have one active resource/education stand at KCC inside the CKD waiting room. The other 2 stands have arrived and are set up, Angela to put information on the stands and have them active as soon as possible. It was suggested to move displays around to the general nephrology room at VH and UH as well.</p> <p>Fred reported that the visits are complete and went well. No serious problems were reported, rather a lot of recognition for the good things being done. Angela has collected feedback, Fred will prepare a report of findings to share with the Renal Executive Committee.</p> <p>The anonymous survey conducted by the PFAC members showed a positive response to PFAC being involved in an education day next fall for the renal patients. This task group is in the process of creating a survey monkey link that will go out with the spring newsletter so we can determine if there would be interest from renal patients and family members in attending a day like this.</p>  | <p>Fred will comprise findings to share at next PFAC meeting.</p> |

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| <p>3.3<br/>3.4<br/>3.5<br/>3.6</p>                 | <p>Patient Transportation Task Group<br/>         Newsletter<br/>         Recruitment &amp; Orientation Task Group<br/>         Patient Experience Coordinating Committee (PECC)</p>                             | <p>Goal is to distribute newsletter in March, please submit articles to Angela. Don and Paul have put together interview questions for Val Cameron, UH Dialysis Charge Nurse; since Val will be on vacation for a few weeks the council has agreed to save her interview for next edition. Suggestion made to interview a Nurse Practitioner for March addition.<br/>         Fred has suggested checking in with Philip to help Angela with newsletter.</p> <p>An orientation survey went to 3 members who completed the Renal specific orientation in August. The hope is to hold an orientation for our 2 new members in the next month.</p> <p>Nothing to report.</p>  | <p>All: Send any submission to Angela.<br/>         Fred will speak to Philip about helping with newsletter.</p> |
| <p>4.0<br/>4.1<br/>4.2<br/>4.3<br/>4.4<br/>4.5</p> | <p>Open Discussion<br/>         Cisco Jabber<br/>         Transplant Awareness/ Kidney Foundation Walk<br/>         The Voice – Council Membership<br/>         OHA Visit<br/>         Meeting Cancellations</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>Don is in the process of starting a walk-a-thon for the summer of 2018, from Windsor to Ottawa. Don has requested help with a sponsorship letter to request support. He intends for the walk to raise money for the Kidney Foundation, Organ Donor Awareness Program and diabetes. The Kidney Foundation will set up information on their website as well as Facebook. Don would like to visit HD units in major cities and is looking for volunteers to plan and go on the road for the cause. Fred suggested that this may be beyond the scope of the PFAC but if members would like to help on their own time and support Don to let him know.</p> <p>Bob has joined The Voice membership.</p> <p>March 23, 2017 the lead for patient engagement is coming to LHSC and would like to speak to patient advisors. If you are interested in having a one-to-one conversation please let Angela know.</p> <p>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.</p> |  |

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| 4.6 | April PFAC Meeting | New manager, April Mullen will be attending the April PFAC meeting. A interactive exercise to votoe on the definition of patient values will also be held. |  |
| 5.0 | Housekeeping       |  |  |
| 5.1 | Next Meeting Date  | Tuesday April 11, 2017 5:00pm to 7:30pm, <b>Kidney Foundation Office</b>   |  |