




**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday May 10, 2016
5:00pm to 7:30pm
Kidney Foundation Office**

In Attendance: George Goodlet (Chair), Fred McInnis (Vice Chair), Bonnie Field, Philip Varughese, Betty Clinton, Deb Bezaire, Janice McCallum, Angela Andrews, Dr. Muirhead, Jarrin Penny, Don Smith

Regrets/Absent: Dr. McIntyre, Dr. Rehman, Robert Barnicoat, Nancy Wilder, Paul Dixon, Mike Smith, Nikki Anderson, Deb Beaupre, Carolyn Ingram

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	Minutes of April 12, 2016 approved as distributed.	
1.2	Additions to agenda	Additions: 3.8 Using number versus name in CKD Clinic 3.9 Transitions 3.10 Save Your Veins	
2.0	Task Group Reports		
2.1	Patient Resource Task Group	Philip reported that one display stand has been ordered, awaiting delivery. Task group is sorting out what is most appropriate to display and who will be most responsible for maintenance. George suggested including Kidney Foundation and Baxter Dialysis Snapshot information. Deb has been unable to confirm an IT dept. representative to discuss changing the PFAC web page address.	
2.2	Patient Feedback Task Group and Satellite Visits	Satellite visit out to Goderich and Stratford completed on May 1 by Fred, Betty and Angela. Among some of the issues patients reported were cost and availability of transportation, cost of parking (at Stratford only, in Goderich there is free parking on the street), privacy, new dialysis chairs, more frequent in person visits from dietitian and social worker.	

		<p>Further discussion regarding feedback around allied health included:</p> <ul style="list-style-type: none"> • Patients felt that using the ipads were not private or personal • Patients would like to have more frequent in person visit from allied health during clinics <p>Janice stated that making changes like these would depend on funding. She would like to see a full visit report to all satellites before making any recommendations.</p> <p>Tillsonburg visit planned for May 16th.</p>	 <p>Renal PFAC Goderich Satellite Visit Report.1</p>  <p>Renal PFAC Stratford Satellite Visi</p>
2.3	Patient Transportation Task Group	Deferred	
2.4	Communication Task Group	<p>Angela reported plans for next edition newsletter to be distributed in June. Angela asks everyone to send any content to either Nikki or herself. Angela shared feedback from a PD patient reader who realized after reading the newsletter she was taking her oral iron medication wrong, this has since been corrected.</p> <p>Angela will set up a time for Fred to interview Nancy Woodcock (dietitian) for newsletter.</p>	<p>Angela will set up dietitian interview.</p>
2.5	Recruitment & Orientation Task Group	<p>Change to terms of reference in that satellite representatives will call into meetings as needed; they will not be required to call into every meeting. Angela will include another advertisement to recruit representatives in next newsletter.</p> <p>Angela and task group will work on creating an outline of the renal program structure for new PFAC members.</p>	 <p>Satellite Advisors Roses and Responsil</p>
2.6	Patient Experience Coordinating Committee (PECC)	<p>Bonnie shared that the Ontario hospitals are required by law to survey patients. Over 8000 surveys have been distributed to patients who have been inpatient or through emergency since 2008, the average return rate is 29.5%. Hospitals are able to analyze data and compare through a shared database. In addition individual services throughout LHSC also conduct their own surveys. The hospital is looking for a way to share what surveys are being conducted across the organization to try and avoid duplication.</p>	

<p>3.0 3.1</p>	<p>Open Discussion CKD Funding</p>	<p>Janice explained that the renal programs across Ontario are funded by the ORN (Ontario Renal Network) and how the CKD monitoring tool calculates revenue based on volumes. There are certain dollar amounts assigned to cover the patients visits, treatment, medication, support etc. The program maintains very precise database of patients movement (e.g. from CKD clinic to dialysis or from dialysis to satellite) that is shared with the ORN each month which dictates funding. Janice confirmed that transportation is not included in funding.</p> <p>Janice shared that for the first time in years there has been a decrease in the volume of dialysis patients across our program. Since revenue is based on volumes this means a shortfall of approximately \$1.6 million. As a result adjustments to match this drop in funding were made to the budgets through various savings strategies. This included changes to staff scheduling, supplies/inventory, eliminating in house physiotherapy support, and the biggest savings came from contract negotiations for our dialyzers, this saved us close to \$1 million.</p> <p>Janice explained that our program has partnered with the ORN over the past two years to review patients in pre-dialysis/CKD clinics. Analysis helps to determine which patients need services most so that resources can be used most effectively (i.e. patient stays with CKD clinic which includes allied health support or general nephrology clinic). The province has decided to use a risk predication scale that determines if a patient will require end stage dialysis. The “predictive criteria” used to measure in this equation has been implemented as April. As a result of this change Janice predicts that our funding will be decreased. Spending in clinics versus what we are being funded for will be closely monitored to ensure we match.</p> <p>George raised concern for people who don’t meet CKD criteria who would still benefit from allied health support. Deb and Dr. Muirhead explained that if a need is identified for patients in general nephrology clinic to see allied health that referral will be made. In the general nephrology clinics it is less likely patients would know that allied services exist, it was suggested that we look at a process to ensure patients are aware or have a place to access this information. Suggestions include giving education pamphlet at registration or creating a poster.</p>	<p>Deb will take back concern/suggestions to clinic leads.</p>
<p>3.2</p>	<p>Volunteer Services</p>	<p>In the past volunteer services assisted physiotherapy to prepare exercise bikes and equipment for patients. As we no longer have that service the volunteers are looking for other ways to help</p>	

<p>3.3</p>	<p>Peer Support</p>	<p>UH and VH dialysis units. Deb will be circulating a document to PFAC to come up with a list of ways volunteers may be of help to our patients (e.g. play cards with patients, bring in an instrument and play music). Angela suggested surveying dialysis patients for feedback. Volunteer Services will come back to PFAC in September to further discuss.</p> <p>George suggested having our own PFAC peer support program to support individuals in our own program rather than going through the Kidney Foundation (KF). Although the KF support program is of great value and so are the invaluable resources it would be of benefit for staff to turn to support people who are familiar with our program to help patients.</p> <p>Janice shared that the ORN has been working with the KF to evaluate the Peer Support Program and has come back with a review/recommendations. From this a focus on the partnership between ORN and KF to provide a Ontario based support program, which we may then be able to piggy back onto in the future as a program.</p>	<p>All – Give top 3 ideas of how volunteer services could be of help. Angela – Survey HD patients</p>
<p>3.4</p>	<p>PFAC members at CKD classes</p>	<p>Carolyn was able to arrange with Sandra and Becky, who run the CKD classes to have a PFAC member at the CKD classes to discuss the PFAC and our role. They are happy to accommodate at the beginning of Class #3. The patient may already be there to talk about their experience with kidney failure. Class #3 is the 3rd Thursday of the month from 1-3 pm at Westmount.</p>	<p>Angela will send out the dates and ask for members to sign up</p>
<p>3.5</p>	<p>Vice Chair Elections</p>	<p>Paul is the winner of the election to Vice Chair, he is not present at the meeting today, Angela will inform him and ensure his acceptance.</p>	
<p>3.6</p>	<p>Planning meeting in June</p>	<p>Planning meeting confirmed for Tuesday June 14 at 5:00pm to 7:30pm at Victoria Hospital, Room B2-116 (right beside the staff library). A meal will be provided.</p> <p>Fred would like to talk about reorganizing task groups at planning meeting. Fred and George will create a draft document of proposed changes to present at the meeting for discussion.</p>	
<p>3.7</p>	<p>Calcium drug shortage</p>	<p>Deferred in Nikki's absence.</p>	
<p>3.8</p>	<p>Transitions</p>	<p>George shared the number of transitions patient have through the entire program. He suggested creating a task group to examine the patient perspective of each of these transitions.</p>	

3.9	CKD Waiting Room	<p>George will be the lead of this work along with Phillip, Don and Deb.</p> <p>Kim, coordinator of the CKD clinic is requesting feedback from PFAC re: calling patients by the last four digits of their PIN number versus their name for privacy. This practice would mirror that the surgery and transplant clinic is doing. Pros and cons discussed by council with varied opinions. No decision was reached.</p>	
3.10	Save Your Vein Campaign	<p>Concerns that this initiative is not being promoted by all practitioners. Angela discussed this with our vascular nurses who are funded by the ORN. Response from the ORN was that there is no support at this time so it seems as though this campaign has fallen off track. Thus new staff or patients may not receive this information. Deb will follow up with Janna regarding next steps.</p>	Deb will follow up with Janna
5.0	Housekeeping		
5.1	Summary of Action Items		
5.2	Next Meeting Date	Tuesday June 14, 2016, 5:00pm to 7:30pm, Victoria Hospital Rm B2-112	