



**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday April 12, 2016
5:00pm to 7:30pm
Kidney Foundation Office**

In Attendance: George Goodlet (Chair), Fred McInnis (Vice Chair), Bonnie Field, Nikki Anderson, Deb Beaupre, Betty Clinton, Deb Bezaire, Janice McCallum, Carolyn Ingram, Angela Andrews, Deb Bezaire / **Guest:** Leah Getchall

Regrets/Absent: Dr. McIntyre, Dr. Rehman, Robert Barnicoat, Nancy Wilder, Jarrin Penny, Paul Dixon, Don Smith, Mike Smith, Philip Varughese

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1.1	Welcome, Approval of Minutes	Minutes of March 8, 2016 approved as distributed.	
1.2	Additions to agenda	Additions: 4.8 Patient members of LHSC committees 4.9 Physician membership 4.10 Transplant Clinic update 4.11 Vital Behaviours 4.12 Showdown in the Downtown 4.13 ICES – Guest, Leah Getchall	
1.3	Volunteer Week	On behalf of the renal program Angela thanked all volunteers for their commitment and volunteer work.	
1.4	Kidney Foundation Fundraiser	Ticket for Yuk-Yuks: The Kidney Foundation has offered 4 tickets for a comedy show fundraising event being held April 21.	
2.1	Satellite Transfer Policy	Jarrin reviewed the policy. Policy is an amalgamation of what was already in place for the region and for the Westmount hemodialysis into one document for the in-centres and satellites to use. Highlights include: Page 2, check list intended for each new start chart to ensure patients are evaluated for their ability to transfer satellites. Appendix A is expanded criteria for the regional	 Satellite Transfer Policy_2016 04 07.do

		<p>satellites for patients who may need a lift. Appendix B lists the processes for each unit.</p> <p>Policy approved by council. Next Jarrin will forward to Drs. Moist and Weir for approval before implementation.</p>	
3.0	Task Group Reports		
3.1	Patient Resource Task Group	<p>Patient Website: Philip suggested changing the site address to include “LHSC” in the title and using bit.do in order to become easily accessible for patients. Janice questioned whether LHSC will support bit.do and changing the web title to comply with LHSC regulations/web security etc. Janice suggested inviting technology specialist to the next task group meeting for further discussion.</p> <p>Philip mentioned that bit.do is able to measure how many people have visited the site and for how long. He could pull this data and share with council if we used the bit.do address.</p> <p>Janice asked Kim Farrow to lead in the creation of a patient website pamphlet.</p> <p>Task group will further discuss the design, best location to capture attention of patients to the materials on the resource stand. Some ideas include coming up with a catchy tagline, neon letters, asking the clerk and CKD staff to point out resources stand as a source of valuable information. Decision made to start with one stand to start to be able to assess value.</p>	<p>Angela will let Deb know when next meeting is booked so that Deb can invite a technology specialist</p>
3.2	Patient Feedback Task Group and Satellite Visits	<p>Satellite visits on April 6th were canceled due to the weather, Goderich and Stratford in the process of being rebooked. Waiting for confirmation from Tillsonburg for a visit on May 17 and Owen Sound for June 7.</p>	<p>Janice will contact administration in Tillsonburg and Owen Sound to confirm dates. Once confirmed Angela will ask for volunteers</p>
3.3	Patient Transportation Task Group	<p>Angela received a list of suggestions from renal social work on Para Transit. Next meeting results will be reviewed and next steps determined.</p>	
3.4	Communication Task Group	<p>World Kidney Day exhibit in Westmount Mall attracted some attention and task group is willing to do this again next year.</p> <p>Nikki volunteered to put next edition of Kidney Chronicle together, Nancy will help with editing. Fred suggested including an interview an allied health member to give patients an opportunity</p>	<p>Angela will arrange interview</p>

<p>3.5</p>	<p>Recruitment & Orientation Task Group</p>	<p>to ask common questions (e.g. leg cramps itchy skin, financial issues) and provide readers with key points from a patient and health care provider perspective. Fred volunteered to lead interview.</p> <p>Fred announced Michele Ivanouski, PD nurse has been recruited as a staff member and will plan to attend starting June. No response to date for our call for an associate advisor. Angela reported that individuals from Tillsonburg and Chatham have expressed interest in becoming satellite PFAC representatives.</p> <p>Angela shared draft criteria for the role of a PFAC satellite representative. See amendment for more details.</p> <p>New advisor orientation packages comprised for delivery by the end of August. Fred reiterated the benefit of having a “buddy system” for new members to bring new members up to speed.</p>	<p>with a dietitian</p>  <p>Satellite Advisors Roses and Resposnil</p> <p>All encouraged to attend rounds:</p> <p>May 5 at 12:00, VH, Sumner Auditorium</p> <p>May 18 at 07:15, SJHC, Shuttleworth Auditorium</p> <p>May 12 at 12:00, UH, Auditorium B</p>
<p>3.6</p>	<p>Patient Experience Coordinating Committee (PECC)</p>	<p>Change Management and Patient Experience task groups have been put on hold until further direction from senior leadership.</p> <p>A family presence policy (updated visitors policy) created and sent to senior leadership for approval, hoping to roll out in October.</p> <p>Patient storytelling will be incorporated into medicine grand rounds in May and into bedside reporting and sessions have been held for pharmacists.</p> <p>Next PECC meeting is scheduled for Thursday April 21.</p>	
<p>4.0</p>	<p>Open Discussion</p>		
<p>4.1</p>	<p>PFAC members at CKD classes</p>	<p>Deferred to next meeting.</p>	
<p>4.2</p>	<p>Vice Chair elections</p>	<p>Angela will send communication to all asking for interest in becoming vice chair, then follow up with a request for email vote prior to next meeting.</p>	<p>Angela send communications to all for interest and vote</p>
<p>4.3</p>	<p>CCO Board of Directors</p>	<p>Janice advised that Cancer Care Ontario (CCO) looking for a renal patient or family members to sit on the CCO provincial board of directors. This board is responsible for overseeing policy making at CCO, improving the strategic plan, annual operating plan and various other responsibilities. There are 6 board committees that help the board of directors fulfill its roles.</p>	

<p>4.4</p>	<p>Save your veins and outside labs</p>	<p>Appointment would be for a 3 year term for a maximum of 10 years. Meetings are held 4-5 times per year in Toronto, with one visit to a partner hospital.</p> <p>Expressions of interest need to be submitted by April 22nd. Angela will resend the information and nomination forms to all.</p> <p>Fred shared his experience of resistance from staff in taking blood from his hand at an outside laboratory. Bonnie reported that she was not even aware of this initiative and that the transplant clinic does not take blood from her hand.</p> <p>Angela will follow up with the vascular access nurses on comments made today and ask that the transplant clinic be re-educated, and she will try to get more of the “save your vein” armbands to hand out. It is the responsibility of the renal patient to ask for blood to be drawn from their hand when visiting an outside laboratory. Angela reported that the ORN is responsible for training/educating outside laboratories and as far as she is aware there is no one in place at this time. Patients are encouraged to contact Angela or Janna Rousom directly with any questions or feedback.</p>	<p>Angela will send out CCO information and nomination forms.</p> <p>Angela will follow up with VA nurse re: transplant clinic phlebotomy</p> <p>Angela will get more “save your vein” arm bands</p>
<p>4.5</p>	<p>Satellite Representatives</p>	<p>See 3.5</p>	
<p>4.6</p>	<p>Update on LHSC PFAC Network</p>	<p>The website portal is now called the “PFAC Network”. Work is underway, all programs have submitted their information they would like displayed. This portal is for advisors who will have a user name and password to sign and see what other councils are working on and be able to utilize resources. Next step is to meet with technology department.</p>	
<p>4.7</p>	<p>Planning Meeting in June</p>	<p>Angela will share date of June planning meeting once confirmed.</p>	
<p>4.8</p>	<p>Members to Committees</p>	<p>Angela and George shared a list of task groups and committees that our patients and family member are involved in – 7 PFAC task groups and 7 other committees within the renal program. Faisal suggested we create a list of all the committees we are being asked to participate in, and then review to determine which are most advantageous.</p> <p>Once complete Angela will share with the Patient Experience Office as they are working on</p>	<p>All : Send any feedback re: task groups/committees to Angela and George</p>

<p>4.9 4.10 4.11 4.12 4.13</p>	<p>Physician Membership Transplant Clinic Update Vital Behaviours Session Showdown in the Downtown ICES – Leah Getchell</p>	<p>creating guidelines for having patients sit on hospital committees, add to the PFAC network and send to Deb and coordinators as a resource.</p> <p>Of the following physicians at least one of them will plan to be in attendance at each PFAC meeting, Faisal Rehman, Chris McIntyre, Peter Blake, Norman Muirhead and Andrew House.</p> <p>Recently in the transplant clinic a few patients expressed confidentiality concerns when having their names mentioned in the very large transplant/medicine waiting room. Last week started using cards which uses the last 4 digits of their health card to call on patient.</p> <p>George participated in the DT / PSW vital behaviours session on April 9. This was a positive experience and reminded all of the importance to share both positive and negative experiences and behaviours.</p> <p>Faisal announced the Sky Diggers concert is being hosted at the Aoelean Hall on September 24 to support the renal patient assistance fund. He will send information and web link to purchase tickets (\$35 each) to Angela to share with the council. Faisal’s goal is to raise a minimum of \$10,000 - \$20,000 that will directly benefit renal patients.</p> <p>Leah Getchell introduced herself as the Coordinator of Communications and Patient Partnerships for the Institute of Clinical evaluative sciences kidney dialysis and transplant research Program (ICES). ICES is a provincial research program that uses administrative healthcare data to do large population research, specifically kidney dialysis and transplant. Leah explained that she has been brought onboard to ensure that all the research we are doing is patient centered. Leah will be reaching out for patient collaborators on some of research work or for a future task group.</p> <p>Leah shared her idea of creating an adult colouring book related to kidney disease as a fundraising idea.</p>	
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5.0	Housekeeping		
5.1	Summary of Action Items	As per Action/Follow up column	
5.2	Next Meeting Date	Tuesday May 10, 2016 at 5:00pm at the Kidney Foundation Office Kidney Foundation Fundraiser - Stand Up for the Cure, Thursday April 21 at 6:30pm, goto www.kidney.ca/london for more information	