

**RENAL PATIENT AND FAMILY ADVISORY COUNCIL
MEETING MINUTES
Tuesday September 12, 2017
5:00pm to 7:30pm
Kidney Foundation Office**

In Attendance: George Goodlet (Chair), Philip Varughese, Betty Clinton, Angela Andrews, Nancy Wilder, John Witteveen, Anne Hutchison, Dr. Rehman, Bob Barnicoat, April Mullen, Cathy DuVal, Emma Klotz, Janice McCallum, Bonnie Field, Deb Beaupre

Regrets/Absent: Dr. McIntyre, Nikki Anderson, Jarrin Penny, Don Smith, Viengkham Chanthalan Sy, Michele Ivanouski

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1 1.2 1.3	Welcome, Approval of Minutes Additions to the Agenda Patient Story Telling	Minutes of June 13, 2017 approved as distributed. Round table introductions; welcome new patient member Jim Harrington and Terri Chanda, Coordinator Regional Renal Program. Angela conveyed condolences on behalf of council to Paul Dixon's family on his recent passing. Fond memories of Paul shared.	
2.1	ORN Update- Janice McCallum	<ul style="list-style-type: none"> -Janice shared an update of the ORN (Ontario Renal Network) vision and priorities -ORN oversees all the planning and funding for all renal care across the province -Ontario Renal Plan II, 2015-2019, developed with input from patients and family members from across the province, ORP III currently in development -Janice shared 3 strategic goals and how LHSC will meet these goals <u>Goal #1:Empowering Patients</u>- ORN developed shared decision making tools for staff in the MCKC clinics to use with patients and families -new start dialysis patients have goals of care discussion with health care providers in dialysis units and documenting it -strengthen Peer to peer support program, a joint plan between ORN and Kidney Foundation, 	 PFAC Update Sept 2017.pptx

	<p>several pilots have been started to advertise better and provide support</p> <ul style="list-style-type: none">-Improving transplant care, looking at how patients move through the transplant process, also the creation of the Transplant Ambassador program where patients who have been through the transplant process act as peer support to those currently going through the transplant work up process-ORN Patient Experience Surveys that were completed over the summer, results coming in November 2017-increased opportunities for patients and families to be part of system initiatives, including PFAC and participating in working groups and projects within the program ,ORN PFAC <p><u>Goal # 2: Integrate Patient Care Throughout the Kidney Care Journey</u></p> <ul style="list-style-type: none">- Improving transplant care, looking at how patients move through the transplant process and identifying gaps that exist in care, streamlining transplant education and resources for patients-Physician and pharmacist group looking at drug and dosing recommendations to be used by primary care providers and family practitioners that will prevent further kidney injury or harm to renal patients-Primary care champions and engagement plan to reach out and educate primary care providers about kidney disease, how to screen for kidney problems, when to refer to nephrologist, etc.-support for end of life care and palliative care, including education for staff-managing patient symptoms using the ESAS scale (Edmonton Symptom Assessment System)- a pilot program going on at UH dialysis unit for patients to report symptoms and staff to help manage symptoms <p><u>Goal # 3: Improving patient's access to kidney care</u></p> <ul style="list-style-type: none">-working with Southwestern Ontario Aboriginal Health Access Centre (SOAHAC) to provide education for staff in the community health centers, about early detection, prevention and modifiable factors to help prevent progression of kidney disease-“Community first approach”- increase available spots and make it easier for patients to do home dialysis or dialysis closer to home at a satellite unit-funding to increase satellite spots at both Owen Sound and Chatham has been approved-tele home monitoring via iPad for PD patients currently being trialed	
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3.0	Task Group Reports		
3.1	Patient Resource Task Group	-plans to reconvene in September some time to discuss the creation of a 'road-map' of where the resource centre will evolve to in the next several years	
3.2	Communications and Patient Feedback Task Group	<ul style="list-style-type: none"> -surveys for gathering feedback from home dialysis patients, incentre hemo patients and satellite unit patients on a patient education/pt. experience session were on hold over the summer due to an ORN survey being completed. The surveys have been sent out and due on September 29. -Satellite unit visits have been completed to both Woodstock and Tillsonburg unit 	
3.3	Patient Transportation Task Group	<ul style="list-style-type: none"> -task group has not met over the summer, plans are to meet again, and possibly request for the LTC rep. to return and update us on the progress of PFAC requests made at last meeting -there have been some good and some bad comments about paratransit since they have implemented the new phone system 	
3.4	Newsletter	-newsletter went out to program and patients in August, the next newsletter will go out in November, please let Angela and Phil know if you want to add anything to the next letter	
3.5	Recruitment & Orientation Task Group	-two new members have been recruited, Sherry Sloan, a UH hemodialysis patient, and Jim Harrington, a transplant patient, we are also in the process of recruiting for a new staff representative	

3.5.1	New Chair	<p>-possibly recruiting for another 2 patient family members also</p> <p>-Angela will send out an email asking for those who are interested in the Chair position to come forward and to submit a short “platform” over the next week, and then voting will be held via confidential email until September 29th where the voted in member will have the chance to accept the position</p> <p>-the new chair will be announced before the next pfac meeting</p> <p>-interested candidates don’t need to be nominated, just apply, but please encourage others to come forward and enter the election if you think they would be a good chair</p>	
3.5.2	Vice Chair Candidates	<p>-we will handle voting in the new chair first and then discuss the vote for the new vice chair at the next meeting</p>	
3.6	Patient Experience Coordinating Committee (PECC)	<p>-there has been no news from PECC or Patient Experience over the summer since Lisa Hawthornthwaite left her role. Jill Sangha has become the new manager for the Patient Experience office, and there is a new interim Director Emily Williams</p> <p>-Bonnie mentioned the disappointment that patient/family council members are feeling after all of the work that has gone on within the council and they feel that everything has fallen apart</p> <p>-George suggested that the renal pfac should make an official complaint to the patient experience about the fact that there has been no communications to pfacs about what is happening in the pt. experience office</p> <p>-Janice and April have meeting with new manager Jill at the end of September to gather more info</p>	
3.7	Other Committee Reports	<p><u>Parkwood Project</u>-Betty is the pfac member of this committee, it is a proof of concept trial- a space at Parkwood is being renovated to accommodate Parkwood residents and rehab patients for hemodialysis, a lot of thought going into the plans, the project is a pilot project</p> <p><u>Accreditation</u>-the first meeting is tomorrow for this project, Philip is the pfac rep for this</p> <p><u>Volunteer Services</u>-John and Emma are pfac reps for this, John reported that Fanshawe and Western students be considered for volunteers with patients in the dialysis units</p>	

4.0	Open Discussion		
4.1	Patient Behaviours in Dialysis Units	<p>-there has been no report from Chatham satellite unit on pfac feedback around a poster about behavior in the unit, there will be a visit out to the Chatham unit in October where we may get more information</p>	
4.2	Emergency Preparedness-Anne	<p>-Anne circulated a LHSC pamphlet for emergency preparedness</p> <p>-there were several questions asked at the last meeting about how this plan is communicated to patients, this is covered on the first section of the pamphlet, Anne has requested that members email her with comments</p> <p>-April suggested that the definition of an emergency be included on the pamphlet</p> <p>-there was a discussion on what the emergency is, Janice shared that the emergency management plan does not differentiate the types of emergency (eg, patients can't get to dialysis vs. something happens in the dialysis units that makes them not be able to perform treatments) and that the pamphlet needs to clarify what is an emergency</p> <p>-pfac feels the pamphlet has too much info; it should be specific to a dialysis patient and not office emergency or pet emergency etc.</p> <p>-pfac feels there should be specific and separate info about hemodialysis patient home emergency or emergency in the dialysis units</p>	<div data-bbox="2050 597 2260 716" data-label="Image"> <p>2017-04-13 Emergency Kits.pdf</p> </div>
4.3	Meeting Space-Angela	<p>-the group discussed the current meeting space pros and cons, decided to try a meeting space at Victoria Hospital on a trial basis to see if we are more comfortable as a group, the cost of parking will be covered by pfac, Angela will investigate a new room and will let everyone know of new location</p>	<p>- please let Angela or April know via email or private conversation if you feel that you have barriers to moving meeting location that you did not feel comfortable mentioning at the meeting</p>
4.4	Overnight Dialysis-Bonnie	<p>-Bonnie discussed her experience switching between doing home nocturnal dialysis and intermittent in-centre dialysis during her summer vacation. Bonnie discussed the physical benefits of overnight hemodialysis and requested that the program look at offering in-centre overnight (nocturnal) hemodialysis to patients</p> <p>-Terri discussed some of the reasoning as to why nocturnal hemodialysis does not work due to</p>	

4.5	Patient Experience-George	<p>logistics such as timing of the water system disinfection</p> <p>-April suggested that pfac request a review of this by Janice, Bonnie will write an official request to Janice on behalf of PFAC</p> <p>-George shared a story of his experiences while being involved with several illnesses at once and several different departments within LHSC at once</p> <p>-he felt there was a disconnect between services, especially when transplant and transplant meds are involved, he feels that transplant patients should always be prepared to advocate for themselves and suggest to different physicians to consult with the transplant team, he would like pfac to discuss how we can help to empower transplant patients to advocate for themselves, and how to improve communication between medical services</p> <p>-George also wanted to bring to the attention of patients/families that 7 day parking passes are good for a total of 7 days throughout the year, and not a consecutive 7 day period, the parking office does not widely advertise this</p> <p>-George also experienced a stay in the hospital where his roommate had visitors non-stop during his visit, he felt this was inappropriate, and that patient washrooms should be specifically marked as for patient use only</p> <p>-April suggested some of George's experiences could also be mentioned at PECC, and will consider some of the other suggestions</p>	
5.0	Housekeeping		
5.1	Next Meeting Date	<p>Tuesday October 10, 2017 @ 5:00pm at Victoria Hospital, Room B2-124</p>	