

RENAL PATIENT AND FAMILY ADVISORY COUNCIL MEETING MINUTES Tuesday April 11, 2017 5:00pm to 7:30pm Kidney Foundation Office

In Attendance: 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, Emma Klotz, Michele Ivanouski, Deb Beaupre, George Goodlet, Anne Hutchison, April Mullen **Guests:** Sandy Jansen

Regrets/Absent: Dr. McIntyre, Nikki Anderson, Mike Smith, Fred McInnis (Chair), Deb Bezaire, Robert Barnicoat, Dr. Rehman, Cathy DuVal

	Agenda Item	Discussion	Motion/Action Plan/Follow-up
1	Welcome, Approval of Minutes	Minutes of March 14, 2017 approved as distributed.	
1.2	Additions to the Agenda	The council welcomed the new Renal Program Manager April Mullen	
2.1	Guest: Sandy Jansen from Pt. Safety and Experience Office, "What Patients Value- An interactive session"	-Sandy discussed the restructuring in the Patient Experience office, Lisa Hawthornthwaite's position has been eliminated, and there is now a manager in the department which will formalize the role of person centred care within LHSC and begin the work to embed the principles within all staff at LHSC -Lisa is currently working with the Mental Health program to help them ramp up their patient experience -Sandy discussed the creation of a "Patient Declaration of Values" -legislation was introduced in 2010 called the "Excellent Care for All Act" which drives quality, patient experience and patient relations in Ontario hospitals -all hospitals in Ontario are required to have a patient declaration of values, LHSC currently has a document called Patient Rights and Responsibilities, but wants to change this -to do this the Patient Experience office is asking the questions "What do you expect, and what do you value when you come into LHSC" to all patients, and to everyone in the community and region	

	1		T
		around LHSC by asking the community to complete a brief survey	
		-Sandy shared some real time results from the survey about what the community values,	www.LHSC.on.ca/yourcareyourway
		"competency" comes in first with the results so far	(please forward to anyone you think
		-there is an online survey, or a paper one as well, please forward the link on	would like to fill the survey out, it
		-Sandy will provide post cards with the link to the dialysis units	closes on April 23)
		-the survey is being reported to the board in mid May, and a finalized version of the declaration will	
		be created which will be shared with all of the PFAC's for feedback	
			Printable Survey.pdf
2.2	Save My Veins Update	-Fred brought the issue to council last year about the Save My Veins campaign from ORN, where	-Angela will send this link on to
		outside labs, as well as transplant clinic are not following the recommendations of ORN to avoid	everyone by email
		drawing blood from arm veins on renal patients who may need a fistula at some point	everyone by email
		-Janice brought this to the ORN, who have decided to evaluate the impact of the Save My Veins	
		program	
		-ORN has gathered feed back from Vascular access case managers, and they want feedback from	
		patients also	
		-Janice asked a number of questions about the program, the following are patient/family responses:	
		 Most on the council had never heard about the program or ever had a health care 	
		provider, including a nephrologist mention the importance of saving their veins	
		 Most have had issues with outside labs, and the transplant clinic not honoring their 	
		request to use their hand veins when having blood drawn, despite them wearing a save	
		your veins bracelet and providing a brochure from the Save my Veins campaign	
		 Most felt outside labs were not aware and/or not promoting the program 	
		 Don suggested that there be a Save my Veins brochure in the CKD binder, and that this 	
		be taught in the CKD classes	
		 The council as a whole agreed that Save My Veins is extremely important, and want the 	
		ORN to further promote and make Save MY Veins a priority	
		The council would like to put an article in the next newsletter to promote the awareness of Saving your voins.	
		of Saving your veins	
L			

2.3	OHA Visit Consultation from PFAC on New	-the OHA (Ontario Hospital Association) visited with advisors and staff involved in patient experience about the work that the advisors have been doing within their areas -they discussed barriers and challenges that advisors have faced -the OHA is gathering this information to help promote and support person centred care	
2.4	Corporate Strategic Plan	-the PFAC has received a request from the LHSC Board for input on LHSC's strategic planning, and their priorities over the next 3 to 5 years -they would like to attend the May PFAC meeting to gather this feedback, we will extend the meeting length beyond 7:30pm to accommodate the agenda if needed	
3.0	Task Group Reports		
3.1	Patient Resource Task Group	-All 3 display stands are now in place at each site in or around the dialysis unit.	
		-Angela had some feedback from the ALU site (VH) that the patients who regularly wait in the waiting room were not happy with the placement of the stand. There was some discussion on the placement; we will start by putting a poster directing patients/families to the stand which is in the kitchen.	
3.2	Communications and Patient Feedback Task Group	-The draft copy of the dialysis unit visit report was sent out to council to review before the meeting. The report has been approved and Angela will forward to Fred so he can officially send to Janice from council.	
		-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; Angela has had a few responses, but not many.	
3.3	Patient Transportation Task Group	-have not heard anything back from Chris Murphy from LTC as of yet. The group intends on sending	

3.4	Newsletter Recruitment & Orientation Task Group	a follow up letter to LTC. -Fred also suggested that the task group will be gathering info from patients who use transportation other than paratransit to see where the pfac can help -Spring Newsletter sent out last week. -If you have any suggestions for articles for the next issue (August) please forward to Philip and Angela. -Selena the social worker at UH is working on an article about financial issues, 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 There will be a renal orientation for new members (Emma and John) on April 26 th .	-Angela will speak to the vascular access nurses about an article
3.6	Patient Experience Coordinating Committee (PECC)	-nothing to report	
4.0	Open Discussion Stories of Illness and Health Don's walk to promote Kidney Disease awareness and Transplant awareness	The Narrative medicine dept. held a Stories of Illness and Health recently, where 3 patients who experienced a stay in critical care spoke -Don reported that he has written a sponsorship letter to hand to potential supporters, and he has created his route that his walk will take	- Michelle will send Angela the info for the next events to send on to Council

5.0	Housekeeping		
5.1	Next Meeting Date	Tuesday May 9, 2017 5:00pm to 7:30pm (possibly extend meeting length if needed) Kidney Foundation Office	