

## RENAL PATIENT AND FAMILY ADVISORY COUNCIL

### Virtual WebEx MEETING MINUTES

Tuesday May 10th, 2022

4:00pm to 6:30pm

**In Attendance:** Kathleen Anderson, Deb Beaupre, April Herod, Terri Chanda

**Minutes:** Ashley Papathanassiou

**Guest Speaker(s):** Steve Young and Saul Galindo

**Regrets/Absent:** Kathy McKay, Pam Ireland, Cathy DuVal

|     | Agenda Item  | Discussion   | Motion/Action Plan/<br>Follow-up |
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| 1.0 | <p>1.1 Welcome!</p> <p>1.2 Meeting Minuets from April</p> <p>1.3 Guest Speakers:</p> | <ul style="list-style-type: none"> <li>Welcome everyone!</li> <li>Meeting mins approved</li> <li>Steve Young and Saul Galindo: From communications department at LHSC. Steve and Saul are new within the last year within communications, and we fall within their portfolio. Communications is here to help support communications from PFAC to LHSC staff/Leadership, social media posts, and our PFAC website. They can offer any assistance with the delivery of PFAC messages, or revamping our website by just submitting an email request to them.</li> </ul>   |                                  |
| 2.0 | <p><b>Items:</b></p> <p>2.1 World Lupus day! May 10<sup>th</sup></p>                 | <ul style="list-style-type: none"> <li>Lupus is a chronic auto immune disease that can damage any part of the body (skin, joints, organs, ect.). In lupus, something goes wrong with your immune system, which is the part of the body that fights off viruses, bacteria, and germs (“foreign invaders,” like the flu). Normally our immune system produces proteins called antibodies that protect the body from these invaders. Autoimmune means your immune system cannot tell the difference between these foreign invaders and your body’s healthy tissues (“auto” means “self”) and creates</li> </ul> |                                  |

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|  | 2.2 Summer Kronicle Planning | <p>autoantibodies that attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body. May 10<sup>th</sup> is World Lupus Day, with the purpose of raising awareness and research funding for further advancements towards finding a cure.</p> <ul style="list-style-type: none"> <li>• April: As someone who suffers from Lupus, it is a disease that can go undiagnosed for extended periods of time, leading to more and more complications. 50% of Lupus patients will experience Nephritis, possibly requiring some renal intervention. Raising greater awareness is crucial to moving towards a cure!</li> <li>• Patient Story: Article provided by Terri, about a previous patient we had named Cole Heessels, a 15-year-old boy who will be representing the province at the 2022 Junior National Championships for wheelchair basketball in Charlottetown P.E.I. Cole received a kidney transplant in 2014, after receiving care from our wonderful staff at ALU.</li> <li>• Article COVID changes: Hopefulness... decreasing numbers in the renal program. Highlight to our patients getting out and enjoying the nice weather (add in sun protection, hydration information, ect.). Vaccine information. Suggestion to support message about getting 4<sup>th</sup> and 5<sup>th</sup> doses, current data for antibodies, and reminder for PPE information/recommendation for immunocompromised individuals.</li> <li>• Put in recommendation: "If you feel unwell, or test positive for COVID 19, contact a member of your Nephrology team to discuss treatment options"</li> <li>• Information Re: K diet, limiting fresh fruit and veg</li> <li>• McCormikc Donation to Renal Patient Fund:</li> <li>• Donation made to Pt assistance fund at KCC:</li> <li>• Camp Dorset: How can we help raise money for the Camp.</li> </ul> | <p>- Terri to get information from ministry about COVID vaccine</p> <ul style="list-style-type: none"> <li>• Ashley to email Lyons.</li> </ul> |

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|     | <p>2.3 Fall Community Event Discussion</p> <p>2.4 Virtual Care</p> <p>2.5 Pre-Transplant weightless study</p> | <ul style="list-style-type: none"> <li>• Possible BBQ partnership with Forest Lawn Funeral Home.</li> <li>• Provide information/education pertaining to kidney disease</li> <li>• Possibly in a park with BBQ or bring your own BBQ. Coven Garden Market?</li> <li>•</li> <li>• Make T-shirts for us.</li> <li>• Look into Kidney Costume for Don</li> <li>• Little kidneys or swag</li> <li>• Bring Perm Cath line, dialyzer, twin bag, ect.</li> <li>• TAPs information, maybe invite TAPs Rep</li> </ul> <ul style="list-style-type: none"> <li>• ORN is doing the initiative in assessing virtual care for our patients and what the future of virtual care looks like. Kathleen sitting in to provide patient point of view for Renal patients.</li> <li>• LHSC VP working with higher level work group to look at improving virtual</li> </ul> <ul style="list-style-type: none"> <li>• Kathleen is taking part in being a Patient advisor on a study for weight loss pre-transplant and how to best approach that for our Renal Patients. Kathleen to keep us updated on how study progresses.</li> </ul> | <ul style="list-style-type: none"> <li>• Ashley to look into Park/Coven Garden Market availability.</li> </ul> |
| 3.0 | 3.1 Recruitment blitz planning.   | <p>- Goal to push for recruitment over the summer. Needing Staff Advisor as well as additional patient advisors.</p> <p>- Goderich patient interested in joining. Ashley to FUP.</p> <p>- Possibility to meet again in person. Terri to FUP with information and provide update next meeting.</p> <p>- Staff advisor needed. Ashley to send email to Management to seek for interested staff</p>   | <ul style="list-style-type: none"> <li>• Ashley to push for recruitment</li> </ul>                             |

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| 4.0 | <p data-bbox="254 277 583 673">4.1 Indigenous Engagement Update</p> <p data-bbox="254 673 583 1422">4.2 Renal Exec.</p> | <ul data-bbox="583 277 1520 1422" style="list-style-type: none"> <li>• Terri to meet with LRCP to help better understand what are the needs of our local indigenous community, to help better implement indigenous supports within the Renal Program. Kathleen provided the name of a local contact that is doing similar work within the community. Kathleen is willing to connect with Terri to aid in assistance.</li> <li>• Follow up on “Should we consider a patient's financial state for transportation when looking at the listing for transition to satellite location: Ethics came back, and agreed its importance, but acknowledged the challenges with inputting a criteria for placement that encompasses something as individual ad fluid as financial state. Review being done looking at overall picture and how implement better referral process to satellite and managing growth and attrition.</li> <li>• Staffing is still an issue at satellite locations, preventing expedited expansion of the program.</li> <li>• PD assistance has launched at Maitland Manor for resident care. Training/funding coming into place for expansion of PD trained staff in this LTC.</li> <li>• Proposal submitted to ORN to create a 2-station training program in Owen Sound for Home Hemo with an LHSC nurse.</li> <li>• ICHD patient volume is growing. HH and PD modalities have seen a decrease in volume. ICHD units have been managing with moving some patient around to facilitate numbers. Ned to push for home modalities to elevate the pressure on ICHD units and improve overall home numbers. <u>Deb suggestion</u>: bringing back the education classes around Home modalities and bringing back the patient story telling that used to take place during these classes. Terri is working with IPAC to reinstate the in-person patient conversations with</li> </ul> |                                  |

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|     | 4.3 Transplant Work Up Desk Assessment | <p>existing dialysis patients to help in the decision-making period of modality planning.</p> <ul style="list-style-type: none"> <li>• Accreditation is set to be next April.</li> <li>• A new contract is being put in place for fistula needles. Training being put in place for ICHD units within LHSC, will then branch out to satellites.</li> <li>• Jane Ridley, Nurse Practitioner in the UH dialysis unit, received the “Strength in the Storm Award” today during nursing recognition.</li> </ul><br><ul style="list-style-type: none"> <li>• Hiring under way for Pre-Transplant Coordinator. Reviewing being done by the ORN regarding transplant process across the province.</li> </ul> |                                  |
| 5.0 | <b><i>Upcoming Meetings</i></b>        | <p><b>Next Meeting Date:</b> Wednesday June 8<sup>th</sup></p> <p style="text-align: center;"><b><i>Up-Coming Meeting dates:</i></b></p>   |                                  |