

Patient-focused Self-management of CKD

Project Newsletter

Issue 5: Winter 2018



Accomplishments: January-March

- **Phase 1:** The environmental scan and scoping review manuscripts have been accepted to the Canadian Journal of Kidney Health and Disease (CJKHD) and the British Medical Journal (BMJ) Open.
- **Phase 2:** Completion of 6 focus groups and 11 telephone interviews.

Results from focus groups and telephone interviews:

- 33 patients and 15 caregivers participated from BC, AB, ON, NS, and NL.
- The majority were female (62%) and under the age of 65 (54%).
- All 5 CKD categories were represented, with most patients (70%) diagnosed with CKD within the last 10 years.
- Patients and caregivers identified the following self-management core themes:
 - Living with CKD (i.e. managing diet, travel, work/school, medication, symptoms, finances, and mental and physical health).
 - Accessing and understanding, relevant CKD information when ready.
 - Emotional, psychological and social supports.

Meet Claire and Chantel Large:

- Claire (mother) and Chantel (daughter) patient partners.
- Claire was on dialysis for 8 years until she received a kidney transplant in 2012.
- Every year they take a trip to celebrate Claire's health and ability to travel.
- They're passionate about advocating for First Nation's peoples.
- They are involved in the Indigenous Patient Council and the Indigenous Peoples' Engagement and Research Council.

Next Steps:

- CKD self-management project update teleconference with patient partners on April 2.
- Face-to-face meeting at Can-SOLVE CKD annual meeting on May 6th.
- Results from phase 2 will be shared in spring 2018 with patients, caregivers, researchers, clinicians and policy makers via presentations and reports.
- A one-day workshop will be held in Calgary, AB on June 13, 2018. More info to come.

