

# PATIENT-FOCUSED SELF-MANAGEMENT OF CKD

## NEWSLETTER



### ACHIEVEMENTS:

- Phase 4: Pre-evaluation study to be published in CMAJ Open
- Phase 5: [Implementation study protocol](#) published in Global Implementation Research and Applications

### NEXT STEPS

- Join us on Wednesday, April 27 at 10am MST for our next Self-Management Team Meeting
- Can-SOLVE 2.0 status pending, we will update you when we learn more
- Do you have any ideas to promote My Kidneys My Health? (e.g., events, social media outlets, etc.) – please [email Sabrina](#)

## PROJECT UPDATES

### My Kidneys My Health – 1 year anniversary!

This March marked the 1-year anniversary of the My Kidneys My Health website launch. Over the past year, we have seen over 3,400 users visiting and engaging with the website. Thank you for your continued support and contributions to this project as we investigate how we can best support self-management for patients with early CKD and their caregivers.

### Phase 5 Implementation study updates

We continue to recruit health care professionals and administrators from Alberta for our implementation and evaluation study. Through this study, we seek to understand how we can support the integration of My Kidneys My Health as part of routine clinical care for people with CKD. We are beginning to analyze interview data to identify tailored implementation strategies, which we will then evaluate late summer/early fall.

### Dissemination activities

During the fall and winter, the Dissemination Working Group has been identifying opportunities to share My Kidneys My Health. Over this time, we have seen a higher average of daily users than in the summer of 2021. We'd like to thank KFOC and the Can-SOLVE CKD Network for their support with dissemination. Here is a summary of the activities:

- 1 manuscript published (phase 5 protocol), 1 upcoming publication (phase 4)
- 9+ social media posts, 1 presentation, 1 patient mailer, various planning meetings internally and with stakeholders
- In May, our website engagement and dissemination work will be showcased at 3 conferences: KT Canada, CSN, and the Nephrology Research Group's Roy Vi and Baay Chair lecture series

Strategy for Patient-Oriented Research



## INTRODUCING BETTY AND LAURINDA

Betty Pearson is from London, Ontario, and is now retired. She spent most of her career as a Hospital/Consumer Health Librarian. As she says, it's not as boring as it sounds, as her profession allowed her to work and travel extensively abroad.

But now Betty finds herself embarking on a new journey, having recently been diagnosed with chronic kidney disease. Betty hopes to manage its progress through diet and has engaged a renal dietitian to learn how to cook and eat differently. She was a "live to eat" kind of person, so it's been a real challenge! Fortunately, technology is helping Betty access great sites like [Mykidneymyhealth.com](https://www.mykidneymyhealth.com), which provides access to valuable resources and a wonderfully supportive community.

Information dissemination and knowledge transfer have been her life's work, so it is in this capacity that she looks forward to becoming involved as a patient partner.



*Betty Pearson*



*Laurinda Ferreira*

Laurinda Ferreira is a 28-year-old from Montreal, Quebec. Her chronic kidney disease journey began in early 2016 after having been diagnosed with Goodpasture's syndrome, an auto-immune disease that directly impacted her kidneys. Since then, she has been treating her CKD with a combination of medications, exercising, and maintaining a CKD-focused diet.

For stress relief, she practices karate and yoga. In her spare time, she enjoys practicing piano, playing video games, and practicing art mediums such as needlework, painting and drawing. She graduated from the University of Ottawa in public relations and currently works as a data analyst and strategic policy advisor.

Her occupation combined with her medical lived experience gives her a unique interest in participating as a Patient Partner, particularly having a desire to make information about scientifically-backed wellness and nutrition more accessible supplementary to the doctor's office.