



BACKGROUND

- Patients with kidney failure require dialysis treatments or a kidney transplant to survive.
- Kidney transplantation offers patients a longer life at a fraction of the cost of dialysis, but many barriers prevent patients from receiving a kidney transplant.
- A patient-led workshop was held to brainstorm roles patients and donors can play in translating kidney transplant research findings into best practices. The **Patient Partner Coalition (PPC)** is a key outcome of this workshop.

METHODS

- The PPC includes 18 patients (i.e., kidney transplant recipients and living kidney donors) from across Canada, a communication specialist, two clinicians and one researcher.
- Monthly PPC meetings are held to translate knowledge about kidney transplant-related research into policy and practice.
- The PPC supports the Canadians Seeking Solutions and Innovations to Overcome CKD (Can-SOLVE CKD) Living Donor Kidney Transplantation (LKD) Project by helping to mobilize their research findings to achieve more living donor kidney transplants.



For more information on our LKD project, go to our website

KEY OBJECTIVE

To see more patients with kidney failure accessing kidney transplant through patient partners playing a key role in disseminating kidney transplant-related research and advocating for change.

RESULTS

Since July 2022, the PPC has met more than 18 times and has spearheaded multiple activities, including:

- Creating a knowledge translation strategy,
- Attending story-telling workshops to produce videos and written stories on their lived experiences ,
- Creating a website,
- Developing 6 topic-specific working groups, such as a Social Media Working Group, focused on completing specific projects as part of the knowledge translation plan,
- Developing a “Transplant First” campaign as a key solution to reduce the human and financial toll of kidney failure.



Although we do not yet know the impact of the PPC, stakeholders have commented that patients have a unique opportunity and authenticity through their lived experiences to disseminate research and advocate for the implementation of best practices in kidney transplant research.

For more information, go to our website

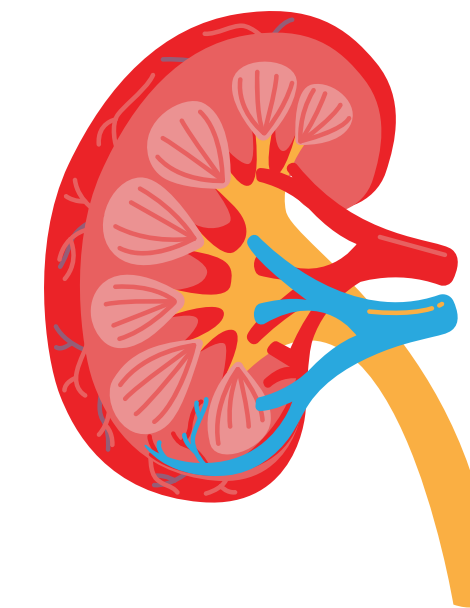


THE “TRANSPLANT FIRST” CAMPAIGN

An urgent call to action led by the Patient Partner Coalition, created to reframe the Canadian kidney care model to prioritize kidney transplant first, as the best treatment for kidney failure.

DISCUSSION

- The PPC can transform the way we conduct patient-partner research, enrich the research that is conducted, and serve as a framework for other research groups.
- Patients and living donors have a unique opportunity, credibility, and authenticity to persuasively advocate for a more transparent and accountable healthcare system.



“The opportunity to have a transplant is life altering. From patients to patients, this initiative to promote ‘Transplant First’ will spread the word to more people with CKD and potential donors to create a clear understanding of the benefits of kidney transplant. I want to be involved so patients can explore the option of transplant early in their CKD journey.”

- Marian Reich, Living Kidney Donor



FOR MORE INFORMATION

Kyla Naylor - kyla.naylor@lhsc.on.ca

Susan McKenzie - susan@kidneyalliance.ca