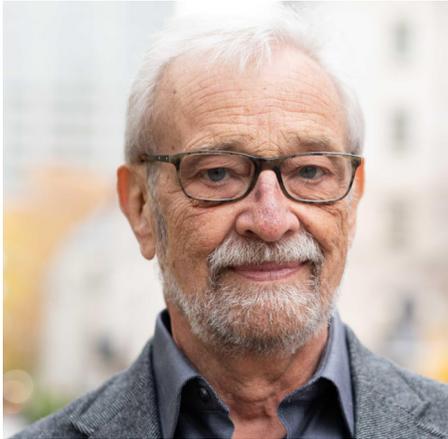




Meet our Patient Partner: Hans Vorster



My name is Hans Vorster, I live in Kingston, Ontario, and I'm a happy man. Some 25 years ago, I was diagnosed with Chronic Kidney Disease resulting from a disease called Focal Segmental Glomerulosclerosis (aka FSGS) which is incurable and even as little as 40-50 years ago would likely have led to an early death. But treatment was possible and has developed on a steep curve over that interval. I was a witness to and a beneficiary of those evolving treatments. Hence I have traveled the full journey of CKD from diagnosis to monitoring and treatment of symptoms through dialysis, in-centre and at home, and finally the transplant of a pre-owned, well maintained and healthy kidney. I feel great and I live as normal a life as any other grey haired old fart, and that makes me a very happy man.

However, none of this would have happened without a crowd of other people, from all the professionals, nurses, physicians, support staff, lab technicians and many more as well, of course, friends and family, caregivers and finally the consideration and generosity of my anonymous donor. This leaves me with a considerable sense of obligation to do something in return. I'm in no position to fund a hospital or perhaps a satellite clinic or even a dialysis chair, but I do have time, and a more or less still working brain, and mostly experience. Therefore, I have chosen to dedicate as much time as I can muster to help in improving the patient experience by working on projects that assure that patients and their caregivers are a fully integrated part of their own care team (Patient Centered Care), that communications among and between the various components of care are fully transparent and accessible and that research conducted into renal disease and others, give full consideration of the impact the research will have on patients, not just the outcomes but the process, by engaging patients at all levels of the undertaking from conceptualization and design through execution, analysis and reporting. There have been great strides made in all these areas to the degree that we can point to a culture shift in the patient-professional medical relationship – and this makes me a happy man!

Mentorship and further exploration:

Priscila Ferreira Da Silva's involvement with Triple I as an Indigenous research assistant has led her to explore the ways Indigenous patients in Manitoba articulate barriers and solutions to HD care for a Master's thesis. Under the mentorship of Dr. Clara Bohm and Dr. Robert Lorway, this proposed study seeks to improve the experiences of Indigenous patients on HD by engaging in storytelling to characterize the persistent systemic forces affecting the wellbeing and quality of care of patients.

Next issue: September 2019

Project Update:

It has been a busy quarter for Triple-I. We have rolled out the survey in all sites and preliminary results are being analyzed.

Two new sites: We are pleased to announce and welcome two new Canadian sites Vancouver and Montreal came on board for Phase 2 of the project.

Phase 1: We are reporting on the process of involving patient partners as co-researchers through their involvement in qualitative analysis of Phase 1 focus group transcripts.

Phase 2: To help with prioritizing the challenges and solutions identified in Phase 1, the Phase 2 survey is being administered at 7 sites across the country and is also available online at betterkidneycare.ca

Phase 3: We are launching into Phase 3 of the project with our upcoming Priority Setting Workshop and Meeting in Winnipeg, June 14-15. We are bringing together patients, caregivers, healthcare providers, researchers and policy-/decision-makers, from across Canada, for a day long workshop to review and refine the results of Phase 2. At the meeting, we will rank and identify the top solutions to address to improve HD Care. These solutions will be trialed in Wave 2 of the Triple I project rolling out in January 2020.

Knowledge Sharing: Over the past two months, we have presented the preliminary findings from Triple I:

- Chronic Disease Innovation Centre, Seven Oaks General Hospital, Winnipeg
- Manitoba Renal Program, Health Sciences Centre, Winnipeg
- Canadian Society of Nephrology Annual Meeting, Montreal
- Can-SOLVE Annual Meeting, Montreal

Thank you for your involvement.

For more information about Triple I, visit: <http://betterkidneycare.ca>; contact Melanie Talson: mtalson@sogh.mb.ca

For more information about CanSOLVE CKD, visit: <https://cansolveckd.ca/>