



Samantha, Ben & Ramona

### Meet our Patient Partner!

My name is Samantha Schellenberg, I live in Winnipeg, Manitoba with my husband, Ben, and my German Shepherd, Ramona. I have had renal complications since I was a baby. When I was 11 I received a kidney transplant from my dad, but that failed around the time I turned 20.

I was on peritoneal dialysis for a couple of years, but I have been on hemodialysis for the last 10. Trying to come by another transplant is very difficult because I have antibodies out the wazoo.

I try to keep a sunny disposition about it all. I'm very lucky that I have a lot of support - from friends and family to doctors and nurses. So when I feel defeated and hopeless, it's good to know I don't have to do it alone.

It helps to have things that I enjoy that I can just throw myself into. Some people meditate to feel at peace. I draw. I also enjoy starting impromptu philosophical and highly theoretical conversations about superheroes (Don't even get me started on Harry Potter).

I am excited to be a Patient Partner and to use my very niche skill set to help with the research that is important to me.

### Engaging Patient Partners in Research:

May 11th, 2021 Six Triple I Team Members (3 Patient Partners and 3 Researchers) participated in a panel discussion and presentation for Clinical Trials BC to describe their experiences and reflections on participating as collaborators in research. The webinar was a success and we fielded questions related to patient engagement in research. It was great to share our patient engagement success with other researchers!

### Publications:

- How to improve Information for HD patients manuscript: revisions requested by CJKHD
- Challenges to interactions in in-centre hemodialysis care manuscript: in progress

### Project updates:

**HUBS of Care Surveys:** asking HD patients and clinicians which health care providers they would most like to see in the HD Unit. 165 patients and 120 health care providers have responded so far! Thank you!

Share your voice! Survey available until June 30th! Thank you!

- Patients/caregivers: [https://is.gd/HUBSofCare\\_PCGsurvey](https://is.gd/HUBSofCare_PCGsurvey)
- Healthcare providers: [https://is.gd/HUBSofCare\\_HCPsurvey](https://is.gd/HUBSofCare_HCPsurvey)



### Project Update: The LENA app

The Lena App has been tested by our team for ease of use and functionality. Next step: finalize the information that Lena will provide to users and roll out prototype for testing at all sites! Thank you to Bitstrapped for your development assistance!