



## Project Update

Over the past few months we have finished consulting with patients and health care providers in Calgary, Edmonton, and Winnipeg. We have begun official data analysis for these Prairie regions. The recruiting phase in the last two sites — Ottawa and Halifax — are underway.

## Patient Partner Highlight

Patient engagement is a top priority of Triple I. We seek to involve patients with real experience to guide the research and represent the patient voice. We are honored to introduce Arlene Desjarlais, a member of the Can-SOLVE patient council and a new patient partner with Triple I:

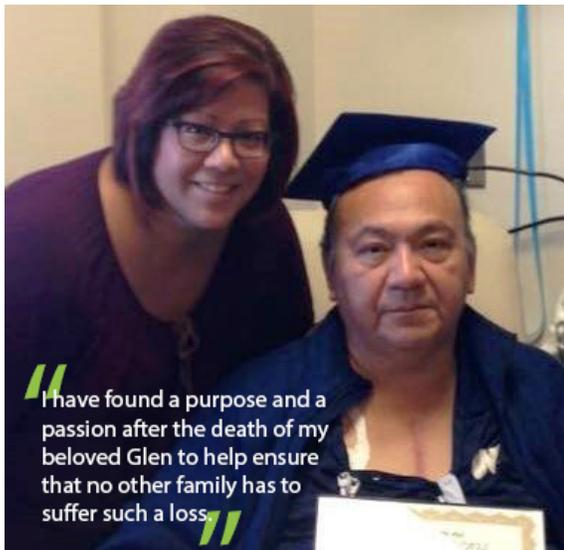


Photo:  
Arlene and Glen Desjarlais,  
Manitoba, CA.

## Words from Arlene Desjarlais

"My husband Glen started dialysis in 2012. As I watched Glen take each labored breath, I knew our lives were forever changed. We had become part of a new, supportive, kidney-family. Glen then went on to PD and we had a normal, active life. In 2015, other health issues saw Glen back on in-centre dialysis, but eventually he was able to start home hemo. At the time of his passing in February 2016, Glen had the freedom to live life fully, and set his own dialysis schedule. During our experience, I learned to be persistent and ask as many questions

as necessary, and that our health system can be flawed at times, so you must speak loudly to be heard. There are patients going through this alone, and unlike my husband they do not have a voice to speak for them, and this could mean the difference between life and death. My life's mission is to carry on Glen's legacy by being a voice to champion all that the renal community is doing to find a cure for CKD, and to raise awareness. I have found a purpose and a passion after the death of my beloved Glen, to help ensure that no other family has to suffer such a loss."

## Project highlight:

Triple I sponsors several research pilot projects that rapidly address specific areas of concern for people on hemodialysis:

Voice-HD is a web application (app) created to enhance communication between dialysis patients and their kidney doctors.

In this research study, the Voice-HD app was developed for patients who receive hemodialysis treatments at out-patient dialysis units. The aim of the study is to evaluate the benefits of using the app to improve the quality of interaction between hemodialysis patients and their kidney doctors. Patients are able to prioritize their health concerns, request medications, and schedule a private conversation with their kidney doctor, all through the features of the web app.

The Voice-HD app is now ready for testing and will be available at several hemodialysis units in Edmonton later this month. Patients dialyzing at Winnipeg hemodialysis units will also be testing the app this summer.

## Next Steps

In the upcoming months, we will be completing our data collection with Ottawa and Halifax. We will analyze the information and work alongside patient partners to interpret and bring forth areas of top priority. These priorities will be taken to the next phase of Triple I.

For more information about Triple I projects or ongoing kidney research, please visit Can-SOLVE CKD website at <https://cansolveckd.ca/>

Next issue: June 2018