

To: Standing Policy Committee on Human Services

I'm writing to you today for selfish reasons; as I am one of the people on the transplant list. I have not been on the list very long, but I anticipate waiting for a transplant donation for many years. Why do I think I will be on the waiting list so long? I am aware of the low organ and tissue donation rates, and my health condition is such, that the transplant rating system (formula used for determining urgency/placement on the wait list), does not position me as critical.

I am 41 years old and have been sick with Liver Disease for 8 years. The liver condition I have is genetically inherited. It will continue to deteriorate my liver slowly, and increase its negative effects on my quality of life. I have already had two major surgical interventions, both have helped alleviate symptoms for a short period of time, but have also subjected me to serious complications and side affects. The best solution for my health condition would be to have a live liver donation. (ie. A healthy person would donate part of their liver to me.) Due to the genetic nature of the disease, many of my family members, who would otherwise be potential donors, are not able to help me.

I sat in on the hearings in Saskatoon, briefly, and choose to write to the Committee to give a voice to the people on the waitlist. The Saskatchewan residents who like me, pray and wait patiently by their phones for years, waiting for it to be their turn for a transplant.

When you take this back to Committee/Legislative Assembly for debate, please keep in mind the people like me- waiting on the list, with our lives on pause, living with constant pain and discomfort. If we were your wife, daughter, sister, brother, father; how long would you want us to wait. What ideas to improve the number of transplant donors would you be prepared to support then, to see real improvements to the organ and tissue donation program provincially/nationally?

What changes do I recommend?

- More Public Education – the general public needs information about what's involved with being a donor, what the options for donation are (live/deceased donor), how this affects the donor and recipients lives.
- More Public Awareness – Inform the public about the need for donations, especially locally.
- Opt Out Registry – Make it easier for Saskatchewan residents to indicate their wishes to participate in the organ/tissue donation program. Investigate an opt out system for those who don't want to be donors.
- Decision Time – Let families/individuals make this important choice when they are not experiencing a stressful emotional circumstance. (ie not at the bedside of a loved one dying)
- Make it easier for people to find donation/transplant information online – This is from my personal experience looking for information, support groups, program details for donors.
- Provide financial support/tax relief – From my personal experience, it has cost our family a lot of money to travel to Alberta for treatment and surgery costs, none of which are covered under my insurance. Of particular interest to me, is options for providing some financial support to living donors (for liver/kidney transplants).

I look forward to following your deliberations. If there are other opportunities to provide feedback or become involved, please let me know.

Mrs. Blaire Prima, [REDACTED]