

Enhancing Organ Donation in Saskatchewan

Cory and Tammy Furman

Organ donation can save and extend lives and enhance the quality of life of many.

Saskatchewan legislators have been tasked with reviewing options to enhance the availability of donated organ tissue in Saskatchewan, to enhance the ability of our health care professionals to save the lives of more people in need. The Committee will hear more detailed technical submissions but we felt it important to provide our personal perspectives at this moment of immense opportunity to enhance organ donation and transplant outcomes from this important work.

OUR PROPOSAL

The Committee should recommend changing the underlying basis of our organ donation system to one of presumed consent – i.e. an opt-out organ donor system, instead of the opt-in system which we currently have. As a part of creating an opt-out system, clear and simple channels to allow a person to opt out if they wish to do so should also be created.

This is the only way to significantly enhance the number of donor organs available in Saskatchewan. Tens or hundreds of additional lives could be saved in Saskatchewan each year. The first step towards a presumed consent environment is socialization of the idea – we believe that the idea is already socialized and that an opt-out system is already widely acknowledged as a sensible step to take amongst the general population.

Saskatchewan could be a leader versus a follower in this important health area by making this change and set an example for other jurisdictions. We could also enhance related medical service availability in Saskatchewan by making this change – specialists and other health care professionals required to perform transplant surgery and procedures could assist patients in related areas.

EXECUTIVE SUMMARY

By world standards, Canada suffers from an abysmally small number of organ donors. If it were possible to enhance outcomes in medical cases requiring organ transplants, with faster organ donation and resulting improved recipient recovery, this would be well received.

We propose dramatically expanding the Saskatchewan organ donor base by changing organ donation to an “opt-out” rather than the current “opt-in” system. Doctors would be authorized by default to obtain organs from available donors in the absence of the donor having “opted out” as a donor. This would improve the number of organs available for transplant, enhance the effectiveness of the donation and matching system, and save more lives. There are also secondary benefits including:

- More lives saved, resulting in enhanced public awareness each time a successful transplant takes place.
- Less waiting time for transplants organs which would minimize times spent by patients in trauma or regular care in hospital. This in turn would result in better personal outcomes and recovery times and allow for the hospitals to serve more patients.
- Improved local medical capability over time. If we need more medical specialists to assist patients locally in these cases, this will over time result in the general availability of enhanced specialist medical resources.
- Expanded availability of specialized transplant-related tools and resources in one or more surgical centres to support these efforts.
- Potential cost savings to the healthcare system by performing more of the transplant surgery here rather than outside the province.
- Lives of additional transplant patients in adjacent jurisdictions could also be saved, and the awareness of the utility of an opt-out system raised across the continent.

There is a confluence of positive factors in Saskatchewan at present which in cooperation will allow for the enhancement of donation and outcomes in the creation of an opt-out system or otherwise.

Only by substantially increasing the amount of available donated organ material can more lives reasonably be expected to be saved.

BACKGROUND

Our Story

Before 2010, Tammy and I were like most Saskatchewan people. We supported organ donation, thought it was a good idea and checked off the organ donor box with the sticker on our health card, when we remembered.

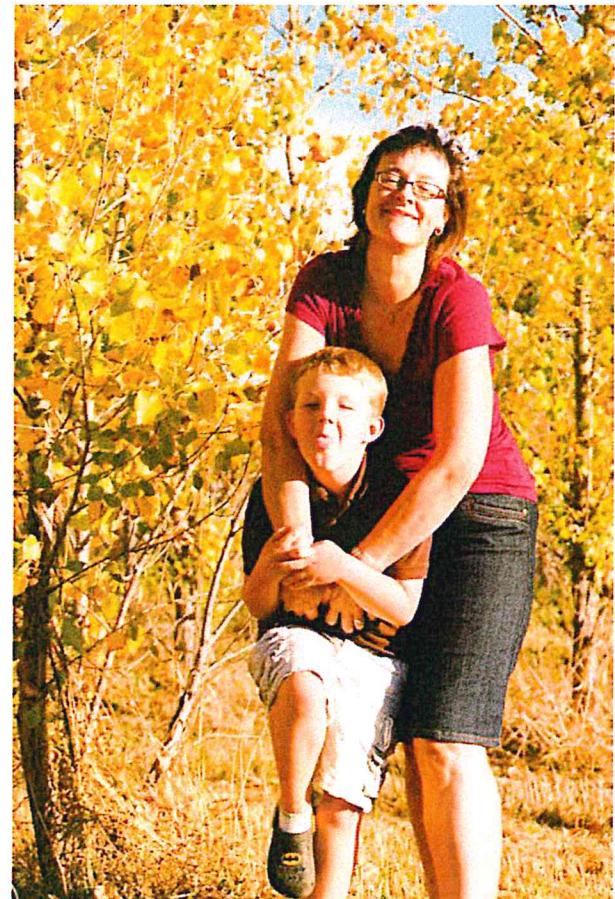
Then, in the winter of 2010, our perspective changed forever. On a two-week family vacation to Hawaii, Tammy was feeling a little under the weather – her malaise continued while we were away, and she was feeling more and more run down so we finally visited a doctor near our vacation site. Like us, he didn't think it was anything too serious but sent us to the local hospital for Tammy to have a blood test and quick checkin with doctors in the ER. We were sent on our way from that review with no indication of anything out of the ordinary – when the blood test results were available a few days later we were told that the liver readings in the test were a little bit off the norm but there was nothing to worry about and to just check in with our doctor when we returned to Regina. Tammy made an appointment with her Regina doctor for the following week and we set about trying to enjoy the remainder of our trip.

Two days later, our situation changed dramatically - Tammy began behaving erratically and it was clear something was very wrong. Late that night Tammy was rushed to hospital on Maui where she was diagnosed in acute liver failure, and was airlifted to a medical facility in Honolulu for further care.

On my arrival at the Honolulu hospital, specialists told me that Tammy's liver was not functioning and barring any response to their intervention, she would require an immediate liver transplant to survive. She was placed into an induced coma in order to avoid potential brain damage from the condition.

Beyond the obvious shock of the situation, including the front end discussions with the hospital about the likely cost of Tammy's care and required operation, all that any of us in our circle could think about was how they would find a donor liver to save Tammy's life. Luckily we had travel insurance and workplace extended medical insurance to cover this and the insurance provider was very helpful, and the hospital staff treated us like family and told me that we shouldn't worry, but all I wanted to know was that there was a donor somewhere out there.

Four days later a donor was found. Following a lengthy recovery, the surgery was a complete success – while Tammy has no cohesive memory of much of that Hawaiian vacation, she has made a perfect recovery and today is as healthy as ever. The lives of my family and our extended circle of family and friends were forever changed by the kind act of a donor family and by the availability of a liver to save Tammy's life.

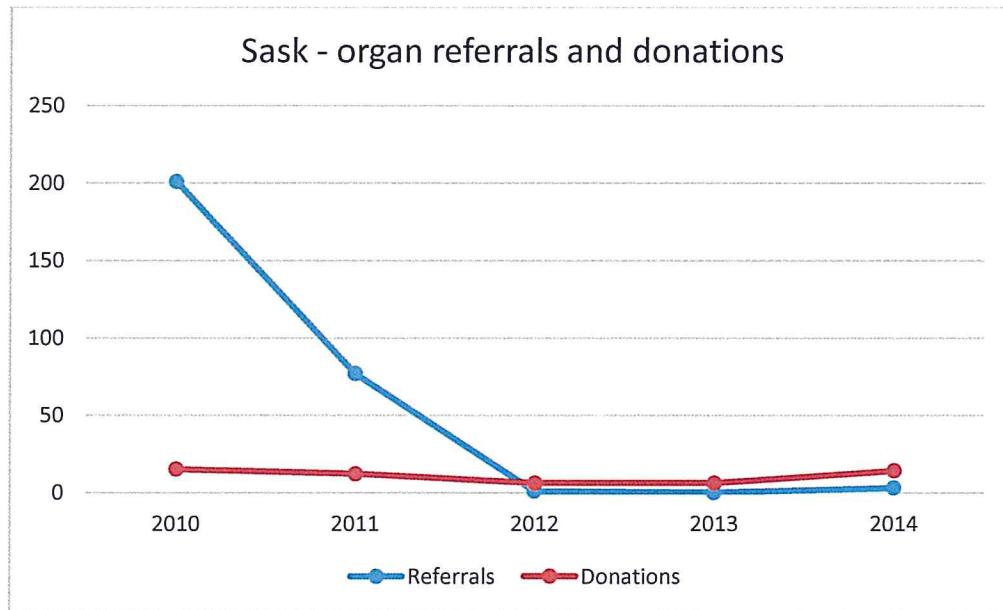


The Current Situation and Environmental Challenges

Since this incident, we have shared our story widely and we have been amazed by how many other families have had experiences, positive or negative, with the organ donation system. Unfortunately, far too many of those experiences have involved a loved one dying while waiting for an organ.

Statistics show that organ donation rates in Canada, for a country of our level of affluence, education and compassion, are disarmingly low. Our family were lucky with the confluence of fate, available medical care and an available organ to save Tammy's life, but had this incident happened in Canada, in the same set of timing and circumstances, we are not convinced that Tammy would have survived. With the lack of donor organs, the odds are strong that Tammy would have lost her life and my young son would have lost his mother. This sort of incident could happen to any Canadian at any time. Organ failure can sneak up quickly and doctors cannot always easily detect the need in time for an orderly approach. In order to effectively treat sudden organ failures and save these lives, we need to ensure that our doctors have access to a sufficient pool of donated organs. To prevent lives from being lost, Canadian provinces must institute a far more robust organ donation system to maximize positive transplant outcomes.

Figures collated by the Canadian Institute of Health Information show that in 2014, 109 people in Saskatchewan were waiting for organ transplants. Three people died waiting. In that year only three potential organ donors were identified and 14 organs were donated. All of the Saskatchewan donations were from brain dead donors and none from cardiac related deaths. The following graph demonstrates organ donor referrals for organ procurement, and organs recovered (from the same CIHI data):



Based on this system we make the following observations:

- Identification and referral of donors is getting worse – from 2010 to 2014 referrals have gone from 77 to 3, with not a single donor referred in 2013;
- Organ donation rates are not improving, despite increased effort in public awareness;
- We are not even getting enough organs donated to cover the number of transplants being provided in Saskatchewan, causing us to rely on other jurisdictions for organs donated; and
- We are not identifying any cardiac-related donors to have donation discussions with their families, identifying a glaring hole in the current organ procurement system and methodology.

The current system relies on donors to have provided explicit instruction to their loved ones about their wishes as a donor. The current system relies in part upon the family being briefed on the donor's wishes and on an imperfect physical identifier (sticker on the health card of the donor). In many trauma care cases, this identification providing the physical indication of the wishes of the donor is not present or easily available. By the time that information is located or the family contacted, the donation opportunity may be lost.

There are many environmental factors to consider in assessing the best way to enhance organ donation in Saskatchewan. The system faces a number of challenges:

- Geographic dispersion of the population – the population of the province is widely distributed. This is a problem both in terms of donors and recipients. Donations must be completed in central surgical facilities. If the organ donation takes place far from the organ recipient, there may be problems coordinating a surgical location.
- Geographic dispersion and size of hospitals – Saskatchewan has many smaller medical facilities and fewer, widely dispersed larger ones. This creates the challenge of educating health personnel in smaller centres about organ procurement and donation awareness.
- Lack of awareness – as our family experienced first-hand, organ donation is an abstract topic until you need it. People who lack direct experience with a loved one, either as a donor or as a recipient, think little about it. Some people also feel a certain amount of uncertainty or hesitation about donation that could be addressed by better public awareness or education.
- Emotional hurdle – there is undoubtedly an emotional hurdle to overcome for medical personnel to discuss the possibility of organ donation with a donor family, particularly in a culture where donation rarely takes place. By enhancing the number of donations this

should become a culturally normalized discussion, which would be helpful in smaller health centres where there are likely community ties between medical staff and donor families which might make the organ donation preparation and discussions even more difficult.

- Lack of organs results in restricted availability of local specialized medical resources to perform types of organ transplant surgery etc.

Given our own personal experience we draw comparisons between the US and Canadian organ donation environments to understand how things might be done differently in other jurisdictions. The number of organ donors per million in the United States is approximately double the number in Canada. Undoubtedly the committee can also learn from practices in other provinces and other countries outside North America. A first glance comparison of the Canadian and US medical systems, for comparative purposes to try and shed some light on synergies, opportunities or challenges between the two of them from the perspective of organ donation leads you to immediately observe the universal healthcare system in Canada, versus the for profit system operated in the United States, may have something to do with this. However, we do not believe that this happens because Americans are any more altruistic than Canadians. Nor do we believe that Canadians have any greater or lesser aversion to the notion of organ donation. [Organ donation rates for example are even higher in Spain than they are in the United States]

The Opportunity

There are multiple approaches to enhancing organ donation in Saskatchewan, all of which would have positive impact. These include [in decreasing order of importance]:

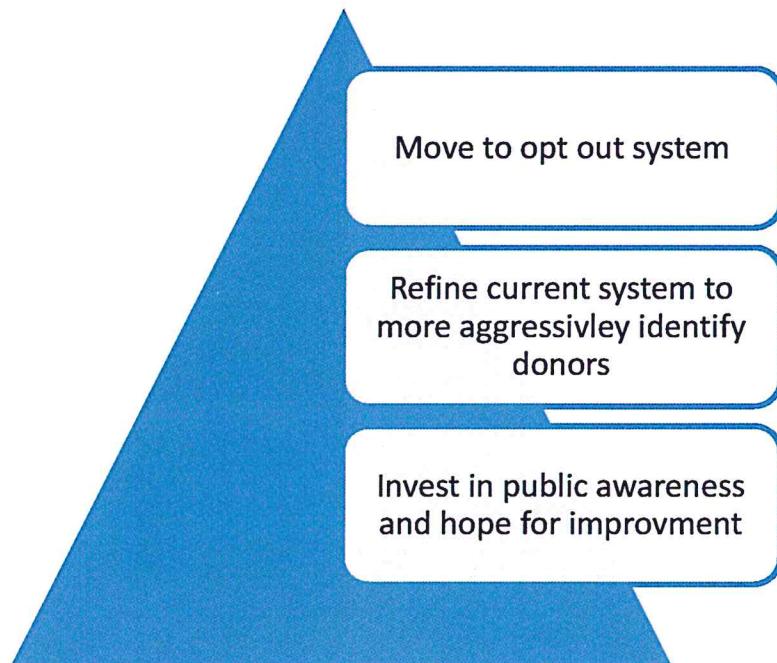
1. Changing the underlying basis of the organ donation system to shift the consent and onus in donation scenarios (i.e. changing from an opt-in to an opt-out system);
2. Fine-tuning the organ donor registry availability and processes so available donor organs could be immediately provided in trauma donor or recipient cases or optimized where donors were being maintained on life support while organ donation arrangements were finalized;
3. Enhancing health worker training to equip care providers with the tools to proactively identify and respectfully solicit donations within the current, or a modified, donation regime – removing the discomfort and creating a greater opportunity and understanding, for either regular care providers or organ procurement professionals to assist in securing and supporting donor families;

4. In the current system, providing an enhanced system of donor indication. For example, capture the donors' choices from their driver's license questionnaire annually, and port this information onto their health records so it is immediately available in hospital or even before patient arrival in hospital in advance-notice trauma cases; and/or
5. Enhancing awareness through greater public awareness of positive outcomes in organ donation cases [investing in a public awareness campaign – perhaps of only nominal benefit].

The Committee should recommend changing the underlying basis of our organ donation system to one of presumed consent – i.e. an opt-out organ donor system, instead of the opt-in system which we currently have.

This is the only way to significantly enhance the number of donor organs. With other refinements in processes and training, tens or hundreds of additional lives could be saved in Saskatchewan each year.

We believe that the hierarchy of available options, with the best and most impactful approach at the top, is demonstrated in the following chart:

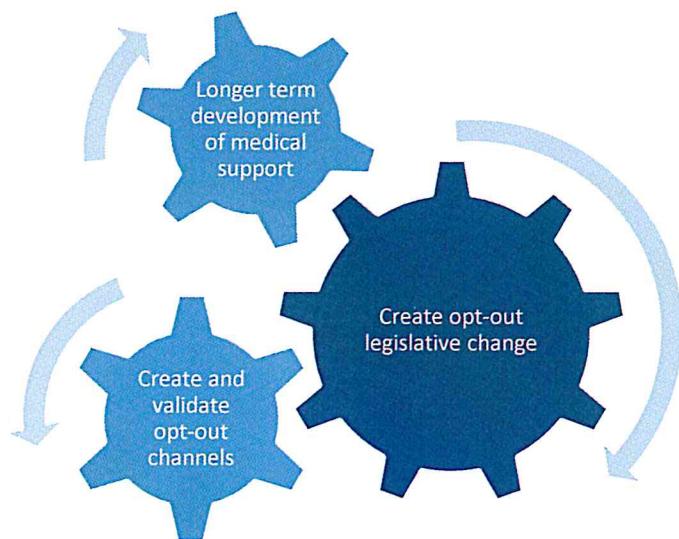


There are several very positive factors which make it easier to contemplate enhancing organ donation outcomes in Saskatchewan. These include:

1. STARS air ambulance service. We now can move donors to a surgical centre for organ donation procedures, and recipients can be moved if necessary to the selected center where the transplant procedures might take place.
2. Childrens Hospital. There is a specialist medical facility under construction in Saskatoon which will cause the movement of significant specialist medical resources to that centre, including doctors who could assist in transplant procedures for children, a vulnerable patient population, and others.
3. There is increasing public awareness of organ donation success stories, which should be facilitated to enhance the public acceptance of organ donation.

WHAT WOULD A MOVE TO A PRESUMED CONSENT ENVIRONMENT LOOK LIKE?

While more research is needed, the steps involved in implementation of a presumed consent approach at a high level would look like this:



1. Change or create the provincial legislation to create an opt-out organ donor system;
2. Create multiple data channels through which a citizen wishing to opt-out of being an organ donor could easily do so, including adding the potential of an opt-out to the SGI

driver's license questionnaire administered each year. For others who don't drive, provide alternate ability for them to opt-out e.g. call centre and online;

3. Create clarity in legislation about when or if donor family can override the donation indication, or presumption of donation indication, by the donor;
4. Cause any opt-out donor indications to be recorded against the driver's license, the provincial electronic health record and in the root level of any government-sponsored common identity service for the donor, so first responders, paramedics and in-hospital personnel can immediately know of the organ donor status of a patient, and medical personnel and social supports for patient families in hospital in non-trauma cases can at appropriate times provide support to families and engage to prepare for organ donation;
5. Consider designation of one or more medical facilities to facilitate organ donation and transplant – i.e. moving donors and recipients to a central location for streamlined surgeries to take place – or else consider creation of an organ donation surgical team to airlift or transport to location to handle organ donation and transport of organ material back to transplant location(s);
6. In the short term, transplant surgery may take place within and outside of Saskatchewan depending on surgical availability but plan over time to develop provincially based specialist expertise to provide transplant services, follow-up support, and related specialist medical counsel in the community;
7. Provide training and support for health care workers to assist in supporting donor families in health facilities throughout the province – perhaps by designating local organ donation specialists on staff, and/or developing a central support center for these staff at the provincial level (i.e. a call center or personnel to visit, assist etc.)
8. Consult with health care workers to ensure that organ donor registry information is captured, updated and maintained in as accessible and contemporaneous a way possible, so organ matching can take place effectively; and
9. Invest in public awareness of the benefits of organ donation facilitating the shift to an enhanced organ donor awareness culture.

Saskatchewan has an existing health care system and network of health care professionals who can provide much of the required support to implement this plan. We just need to get them the organ donations and other necessary supports to save more lives.

EXPECTED RESULTS

We expect our proposed solution to result in:

- Significant increase in donor organ availability;
- Significant decrease in organ donation wait times for recipient patients;
- Better surgical and recovery outcomes for recipients by shorter wait times for compatible organ donors;
- Development of a public awareness and culture accepting of the significant increase in lives saved;
- Occasional opportunity to help recipient patients outside the province;
- Longer term development and enhancement of added specialist medical expertise in the province;
- Cost savings compared to current system which could be reinvested in taking care of more patients and performing more organ transplants.

Everyone Benefits

Everyone is a potential beneficiary in an opt-out donation framework – any citizen can be a donor or a recipient.

CONCLUSION

Enhancing organ donation rates in Saskatchewan is an important objective.

We encourage Saskatchewan legislators to be bold in their pursuit of this objective, by creating a presumed-consent donation environment, coupled with education for the public and education and training for health professionals throughout the province. By enhancing the availability of donor organs, along with enhancing the health information flow to maximize the ability of our health system to capitalize on the availability of matching organs to save the lives of recipients awaiting transplant, the maximum number of lives will be saved.

Thank you for your time and action on this issue.

Cory & Tammy Furman