STANDING COMMITTEE ON HUMAN SERVICES

SECOND REPORT OF THE TWENTY-EIGHTH LEGISLATURE

Inquiry into Organ and Tissue Donation

November 28, 2016
LEGISLATIVE ASSEMBLY OF SASKATCHEWAN

Legislative Assembly of
Saskatchewan

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To the Honourable Members of the Legislative Assembly of Saskatchewan:

I have the pleasure to present the second report of the Standing Committee on Human Services. This report outlines the committee's findings and recommendations on its inquiry regarding improving the rate of organ and tissue donation in Saskatchewan. After considering all testimony and written submissions, the committee makes 10 recommendations.

Respectfully submitted on behalf of the committee,

Dan D'Autremont, Chair
Standing Committee on Human Services

Composition of Committee

Dan D'Autremont, Chair
Cannington

Nicole Rancourt, Deputy Chair
Prince Albert Northcote

David Buckingham
Saskatoon Westview

Danielle Chartier
Saskatoon Riversdale

Mark Docherty
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Regina Pasqua

Roger Parent
Saskatoon Meewasin

Hon. Nadine Wilson
Saskatchewan Rivers

Former Committee Member

Greg Lawrence, Chair
Moose Jaw Wakamow

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Executive Summary

The Standing Committee on Human Services conducted an inquiry respecting improving the rate of organ and tissue donation in Saskatchewan from May, 2016 through November, 2016. Public hearings were held in both Regina and Saskatoon, and the committee heard 15 presentations in total. Twenty-six written submissions were received.

After careful consideration of the testimony and written materials provided, the committee makes ten recommendations to improve the rate of organ and tissue donation in Saskatchewan. These recommendations are listed on page 29.

Definitions of common terms used in this report are provided on page 4. Themes emerging from the hearings are outlined on pages 5 through 20, and summaries of individual presentations to the committee begin on page 21.

Terms of Reference

On May 19, 2016, the Legislative Assembly of Saskatchewan ordered:

> That the Standing Committee on Human Services, in accordance with rule 149 of the *Rules and Procedures of the Legislative Assembly of Saskatchewan*, shall conduct an inquiry and make recommendations to the Assembly respecting improving the rate of organ donation in Saskatchewan; and
>
> That the said committee shall hold public hearings to receive representations from interested individuals and groups, and report its recommendations to the Assembly by November 30, 2016. [1]

On June 8, 2016, the Legislative Assembly appointed Danielle Chartier to the committee for the duration of the inquiry through the following order:

> Ordered, That the membership for the Standing Committee on Human Services shall be expanded to eight members with the addition of the Member for Saskatoon Riversdale (Ms. Chartier) for the duration of the inquiry concerning the rate of organ donation in Saskatchewan as ordered by the Assembly on May 19, 2016.[2]

The steering committee, consisting of Greg Lawrence, Chair and Nicole Rancourt, Deputy Chair, met on May 31, June 6, and June 15, 2016 to determine how to proceed with the above order. On June 15, 2016, the Standing Committee on Human Services adopted the steering committee's report outlining the committee's work plan. This report included the dates and locations for the public hearings as well as the deadlines for the public to submit documents and request to make oral presentations.

A province-wide media release was sent to 91 newspaper, radio, and television outlets on June 21, 2016 to inform the public of the hearings and invite input. Subsequent media reminders were sent in advance of public hearings. Twitter posts reminded the public of submission deadlines and provided information on committee progress. An informational flyer was distributed to participants in the Transplant Trot event on June 20, 2016.

An advertisement giving notice of the committee's hearings was placed in each Saskatchewan daily newspaper on July 16 and August 13, 2016. The *Leader-Post* and *The StarPhoenix* published the advertisement again on August 20. Each Saskatchewan weekly newspaper published the advertisement during the week of August 8 or August 15, 2016, and the advertisement ran on Facebook from August 15 to September 14. Information was also updated regularly on the Legislative Assembly of Saskatchewan website.

On June 6, 2016 the steering committee approved a list of stakeholders to be invited to make presentations and/or written submissions to the committee, and on July 13, 2016 these letters were sent out. Notices regarding the hearings were also placed in all the participants' packages at the Transplant Trot fundraising event in Regina on June 20, 2016.

Once the deadline for oral presentations had passed on September 2, 2016, the steering committee approved the agenda for the public hearings. The dates and locations of the hearings were as follows:

September 6, 2016 — Regina
September 7, 2016 — Regina

September 12, 2016 — Saskatoon
September 13, 2016 — Saskatoon

On October 19, 2016, Greg Lawrence resigned as committee Chair and, by order of the Standing Committee on House Services, he was replaced by Dan D'Autremont on the Standing Committee on Human Services. Later that day, Dan D'Autremont was elected by the Standing Committee on Human Services to preside as Chair.

Public Hearings

The Ministry of Health made the first presentation to the committee on June 2, 2016. Additional presentations were heard on the dates outlined above.

The committee heard 15 presentations in total, 11 in Saskatoon and four in Regina. Each group or individual appearing before the committee was given 30 minutes to make their presentation. A 15-minute period to allow for questions by committee members followed. Seven presentations were made on behalf of an organization, and eight were presentations by private individuals. The committee received 10 written submissions and four documents responding to follow-up questions. Thirty documents were tabled in total.

Terminology

Deceased Donation — The donation of an organ or tissue by an individual who is deceased.

Donation after Cardiocirculatory Death (DCD) — Potential DCD donors are patients on life support who have not met the criteria for neurological death, but their heart is not expected to keep beating once life support is removed. The patient experiences cardiocirculatory death once life support is removed and the heart permanently stops beating.

Donation Physicians — A critical care physician tasked with donation advocacy, developing and implementing programs related to organ donation, and training and educating front-line staff. These professionals may be involved in performance monitoring, coordinating organ donation organizations and other support services, conducting research, and ensuring accountability for the organ donation system. They also medically manage organ donors and operate independently of attending physicians or transplant physicians.

Living Donation — The donation of an organ, portion of an organ, or tissue by a healthy individual.

Mandatory Referral — The requirement that all deaths or imminent deaths in hospital critical care units be referred to an organ donation organization. This triggers the system of health care professionals to advance a potential donation through successive steps in the donation and transplantation process.

Neurological Death — Death due to the permanent loss of all brain function.

Presumed Consent — A system whereby the government assumes all people have consented to be an organ donor in the event of their death.

Introduction

Organ and tissue donation is an important issue for the people of Saskatchewan. Not only does it save lives and drastically improve the quality of life of recipients, a strong transplantation program can pay for itself in terms of cost savings to the health care system and tax revenues realized by returning people to health.

The committee heard from several individuals who described their own or a loved one's personal journey through the donation and transplant system. They described their shock at diagnosis, the physical decline, mental anguish, and toll the illness took on their quality of life, income, and loved ones. These stories resonated deeply with committee members who could put a human face to the struggles faced by those awaiting or undergoing a transplant and the joy of those who were able to return to a healthy life after a transplant. Committee members found their input to be invaluable in subsequent deliberations.

According to Mr. Wyatt from the Ministry of Health, the impact a single donor can have is significant. A single donor can save up to eight lives and benefit 75 others through tissue donation. [3] Unfortunately, donation rates have plateaued in Saskatchewan while the number of people awaiting a transplant continues to increase. Mr. Wyatt stated that a person is six times more likely to need a transplant than to become an organ donor after death. [3]

While studies have indicated that up to 90 per cent of the population support organ donation, [4] organ donation rates in Saskatchewan are among the lowest in Canada. The committee learned that a number of factors contribute to the rate of organ and tissue donation realized.

Jurisdictional Comparison

Spain has the highest organ donation rates in the world at 39.7 donors per million people. [5] This is primarily due to deceased donation. Croatia, Malta, Belgium, Portugal, and the United States all have rates higher than 25 donors per million people. [6] Canada's donation rate is 15 donors per million people, and Saskatchewan's rate in 2015 was 9.9 donors per million people. [7]

Deceased Donation

A deceased person may donate tissue, but in order for a deceased person to donate organs, the potential donor must be on life support in a critical care unit of a hospital. In Saskatchewan, criteria indicating neurological death must also be met. Only 1 to 2 per cent of all deaths meet these criteria. [7, 8]

Since 2006, Canada's deceased donation rate has increased by 29 per cent, and it is now among the top 20 in the world. [5] The actual number of transplants performed increased by 23 per cent in the same time period. [5] This was primarily due to organ donations from deceased donors. British Columbia (BC), Ontario, Quebec, and Nova Scotia are the leaders in Canada for their rate of deceased donation. [5] Saskatchewan's rate of 8.8 deceased donors per million people is below the Canadian average of 17. [9]

Saskatchewan had 11 deceased donors last year. [7] In 2014, Saskatchewan only identified and referred three potential deceased donors to the Saskatchewan Transplant Program. [10] These donors contributed the organs for 14 of the 26 transplants in Saskatchewan that year. [10] Twelve organs had to be acquired from other jurisdictions.

Living Donation

An individual may elect to be a living donor by donating a kidney, a portion of their liver, or other tissue to a person in need. In Saskatchewan, only 2.7 living donors per million people are realized per year compared to 15.7 in Canada. [9] Alberta, BC, and Ontario are close to achieving the national target of 20 living donors per million people. [5]

Ms. VanDeurzen from the Kidney Foundation of Canada indicated that 75 to 80 per cent of the people on the transplant wait-list in Canada require a kidney transplant. [11] A kidney transplant can more than double a patient's life expectancy and save the health system $33,000 to $84,000 per year per patient for dialysis. [11] Dr. Moser of the Saskatchewan Transplant Program stated:

> But when you look at the math — that's my background — you actually don't need a 15-page report to tell you that it's extremely cost effective. You just have to look at increasing the number of donor kidneys available to the province by about six a year. That's all you have to do. And somewhere around there, the program pays for itself. [12]

Organ Transplants Performed in Saskatchewan

Currently the Saskatoon Health Region performs kidney transplants from living and deceased donors, and both Regina and Saskatoon perform cornea transplants. The Saskatchewan Transplant Program also has a living bone donation program.

Liver, lung, and heart transplants are performed in Edmonton. In these cases, transplant recipients must reside in Edmonton for a period of time before and after the transplant to receive care from the transplant team in Alberta. Several presenters referenced the financial burden this places on transplant recipients and their loved ones. Various charitable organizations and the Government of Saskatchewan provide some degree of funding to help defer the costs.

Long-term care and maintenance of individuals who require or have received a transplant is undertaken in Saskatchewan.

Organizations Coordinating Organ Donation

Canadian Blood Services

Canadian Blood Services is the national leader and coordinator of organ and tissue donation in Canada. It works within a network of agencies, associations, and groups across Canada to coordinate and provide services to support provincial programs and facilitate collaboration between network partners.

It operates the Canadian Transplant Registry, which links people awaiting a transplant to a donor; the kidney paired donation program in which a living donor donates a kidney to the network in return for a match being made for their loved one; and the highly sensitized patient registry to find national donors for hard-to-match recipients. It develops policies and best practices; conducts research; provides education; and collects, maintains and monitors system performance data from partner jurisdictions across the country.

Saskatchewan Transplant Program

The Saskatchewan Transplant Program provides assessment for transplant, provides care for organ recipients, and oversees the transplant program in Saskatchewan, but they also work closely with organ donation organizations who obtain organs for Saskatchewan recipients. They educate and advocate for both transplant and donation.

The program itself is administered by the Saskatoon Health Region, but they operate out of two offices, one of which is administered by the Regina Qu'Appelle Health Region. Seventeen staff are employed in Saskatoon, and 5 are employed by the Kidney Health Centre in Regina. [13] Registered nurses provide 24-hour on-call service to assist front-line staff when an organ donation event is triggered and to answer questions.

Organ Donation Process Overview

Mr. Richardson from Deloitte provided an overview of how an effective donation and transplantation system might operate. [14] He outlined the functions as follows:

1. Front-line service delivery
    - identifying potential donors
    - approaching the family to obtain consent
    - referring the potential donor to an organ donation organization
    - screening and matching
    - recovery and processing
    - storage and distribution
    - organ and tissue utilization
    - transplant

2. Functions to enable front-line service delivery
    - public awareness
    - hospital engagement
    - provider education
    - policies and procedures
    - provincial coordination

3. System supports
    - registry
    - performance management
    - quality assurance
    - research
    - information management and information technology
    - legislation and provincial policy

Dr. Nickerson from Canadian Blood Services noted that potential donations are lost at each step in the process due to a variety of factors. Ms. Duncan reiterated that observation: "A system procuring organs is only as good as the culture of the system that is doing it, and potential donors are lost in Saskatchewan."[15]

Key Components of Systems with High Donation Rates

Countries with the highest deceased donation rates share similar features. Ms. Schimpf from the Saskatchewan Transplant Program and Ms. Young from Canadian Blood Services referenced the *Call to Action*, a national strategy released by Canadian Blood Services in 2011. It describes research conducted into successful organ and tissue donation systems in other jurisdictions and contains recommendations on how to improve the organ and tissue donation rates in Canada. The Ministry of Health also presented the key elements of a successful system and recommendations outlined by the Saskatchewan chronic kidney disease program steering committee. Based on jurisdictional research and best practices, different presenters focused on different elements and best practices from high-performing jurisdictions.

Key elements of successful organ and tissue donation systems in other jurisdictions include:

- a stand-alone organ donation organization/coordinating authority
- donor physicians
- donation coordinators
- donation after cardiocirculatory death (DCD) programs
- mandatory referral
- intent-to-donate registries
- public and professional awareness and education
- consistently implemented best practices
- performance measurement and quality control
- accountability for results
- hospital capacity to support the system

Several presenters stressed that implementing one element does not translate into higher rates alone. A systemic approach must be taken to incorporate several of these elements before results can be realized. For example, Mr. Richardson of Deloitte pointed out that a mandatory referral program can significantly impact organ donation rates, but without educating staff on how to identify potential donors and approach the family to gain consent, it won't correlate to increased transplants. Provincial coordination is also key to ensure all the hospitals are doing their part consistently to increase the donor pool.

Different presenters focused on the effectiveness of different elements. The Ministry of Health, Saskatchewan Transplant Program, and Canadian Blood Services all honed in on the effectiveness of

DCD programs, mandatory referral, donation physicians, performance measurement and accountability, and public and professional awareness and education.

Addressing Organ Donation Rates

Stand-Alone Agency

Staff from the Saskatchewan Transplant Program currently work with dying donors and their families as well as with transplant recipients, and this results in a perceived bias and mistrust from the public who may believe that end-of-life care is diminished because the front-line service providers represent the transplant community. For this reason, Ms. Schimpf stressed the importance of maintaining a separation between donation physicians, attending physicians, and transplant physicians. She said, "The separation of transplant programs and donation organizations protects against actual and perceived conflicts of interest." [9]

Ms. Schimpf also indicated that the two focus areas, donation and transplantation, compete for limited shared resources. In terms of care and advocacy, the Saskatchewan Transplant Program must chose at any one point whether to focus on the transplant or donation side because they are tasked to focus on both sides of the coin.

The governance structure of the Saskatchewan Transplant Program further hampers its ability to advocate, coordinate, or standardize processes for organ donation. The program is administered by the Saskatoon Health Region; however, one of its two offices is the Kidney Health Centre, which is administered by the Regina Qu'Appelle Health Region. Ms Schimpf stated, ". . . the division between the two offices creates a very complex and sometimes awkward governance structure." [16] Unclear authority also makes collaboration and standardization between health regions difficult. Ms. Schimpf goes on to say, ". . . you can imagine that confusion and complexity increases even more to reach out to the other health regions in our province." [16]

The Saskatchewan Transplant Program recommended that a separate organ donation organization be established and donor physicians be hired to support the donation side so that important changes can be implemented. The governance structure of such an organization should be such that it would allow donor physicians to go into the various health regions to educate staff and advocate for programs and best practices that are consistent throughout the province. Dr. Fenton agreed that all transplant funding should be independent of regional health authorities' funding and that dedicated funding for an organ donation organization should be implemented. Mr. Richardson noted that jurisdictions with high rates of organ donation typically have a stand-alone organization tasked with overseeing organ donation.

Donation Specialists

Donation Physicians

Donation physicians are a key component of high-performing organ donation systems. A donation physician would typically be an intensive care unit (ICU) physician who would operationalize mandatory

referrals, educate front-line staff, and champion DCD programs and best practices. These professionals have the knowledge and education to be able to form necessary links within the network of organizations so that matches for transplant can be made. They also have the technical ability to analyze performance data to identify missed opportunities, conduct pertinent research, and assign accountability for programs within the system. Saskatchewan is one of the few provinces that does not employ donor physicians.

As Ms. Schimpf from the Saskatchewan Transplant Program stated:

> Donation physicians have been in place in many of the other provinces across this country, and by far they have made it possible to increase organ and tissue donation rates in this country. Without their assistance to advocate, to educate, to build programs, success in changing anything for organ, specifically deceased organ donation, is bound for failure. [9]

The Saskatchewan Transplant Program proposed that two part-time donor physicians be hired: one in Regina and one in Saskatoon. Dr. Mainra of the Saskatchewan Transplant Program and Mr. Richardson from Deloitte suggested that extensive additional training for this role would not be required since current ICU physicians and emergency doctors already have knowledge pertaining to organ donation and the care of organ donors. Since an organ donation occurrence is infrequent, a donation physician's expertise need only be called for when a donation is imminent; however, donation physicians' time would need to be protected in order to allow them to work on research, programming, putting best practices into place, and educating staff. Mr. Richardson suggested that donation physicians could also help to coordinate a separate organization and governance structure for a donation organization.

Donation Coordinators

Donation coordinators typically are registered nurses trained in the organ donation process. They help to identify potential donors and refer them to an organ donation organization who can find a suitable match. They are also trained in obtaining family consent and implementing best practices in caring for donors. Donation coordinators are currently being used in Saskatchewan.

Improving Identification

Donation After Cardiocirculatory Death

As safety standards improved and helmets became mandatory, the number of potential donors meeting the criteria for neurological death plateaued. DCD programs expand potential donor criteria to include people whose hearts will stop beating with the cessation of life support but who do not meet the criteria for neurological death.

Since 2006, Canada's deceased donation rate has increased by 29 per cent, and Canadian Blood Services attributes this positive gain primarily to the implementation of DCD programs. [5] Ms. Schimpf from the Saskatchewan Transplant Program stated, "DCD is responsible for the increase in deceased donation we see as brain death plateaued, as I said. It is strictly because of DCD." [16] Nova Scotia, Canada's top performer, has implemented a DCD program which accounts for a third of all donations made in that province. [7]

Dr. Nickerson from Canadian Blood Services indicated that a DCD program has the potential to increase the percentage of potential donors from 1 to 2 per cent to nearly 5 per cent, [8] and Ms. VanDeurzen of the Kidney Foundation of Canada stated that the number of organs available could increase by 20 to 40 per cent with the implementation of a DCD program. [17]

Saskatchewan's numbers had remained flat since 2007 but are beginning to show some improvement with the development of DCD criteria in the Saskatoon Health Region. [5] Ms. Schimpf cautioned that while DCD programs are an important piece to improving donation rates, donor physicians are imperative to the success of these programs. Ms. Schimpf stated:

> Saskatoon Health Region has developed a DCD program, but unfortunately we have stalled out because we lack donation physicians in this province. So we have been unable or very slow in moving forward to bring that program to fruition. Significant gains will not be made without donor physicians in our program. [16]

Dr. Fenton indicated that since potential donors need to be on life support, they are typically identified in an ICU. The staff of these units first need to be educated on the criteria used to identify potential donors in order for a DCD program to be effective.

Donor physicians could be involved in developing and championing DCD programs, educating front-line staff, creating links in the organ donation system to support the program, and conducting performance audits to identify areas for improvement and ensure accountability for the program's success.

Increasing Donation by Seniors

There is a misconception that seniors are too old to donate. The Ministry of Health and Ms. L'Oste-Brown both identified seniors' donation as an important opportunity that is not being utilized. Ms. Young from Canadian Blood Services stated:

> With organs, we encourage you not to use things like age rule-out. Every organ donor is offered. You may have someone in the highest, most sickest category that would be willing to take a compromised, much older donor, and in fact have many years of successful outcomes as a result of it. [18]

They indicate that educating front-line staff on this matter is key to increasing organ donation rates by seniors.

Improving Referral

Once front-line staff have identified a potential organ donor, the Saskatchewan Transplant Program is contacted. This triggers the system of health care professionals to advance the potential donation through successive steps in the donation and transplantation process.

Mr. Furman provided an example illustrating the low referral rate in Saskatchewan. In 2014, 26 transplants occurred in Saskatchewan, but only three donor referrals were made. [10] These donors all met the criteria for neurological death, and they contributed 14 organs for transplant. [10] The remaining organs for transplant were obtained from other jurisdictions.

Mandatory Referral

Mandatory referral is the requirement that all deaths or imminent deaths in hospital critical care units be referred to an organ donation organization. In Saskatchewan, this organization is the Saskatchewan Transplant Program.

Dr. Nickerson from Canadian Blood Services pointed out the effectiveness of a mandatory referral program, using Manitoba as an example. He said:

> And I'll just give you where mandatory referral has had an impact. In 2014 in Manitoba we had 24 donor referrals. With the implementation of a regional health policy of mandatory referral to the Transplant Manitoba program in 2015, we were up to 129 referrals. So we went from 25 to 129, and this year alone, in eight months we've had 163 referrals to the program. [8]

Dr. Nickerson cautioned that these results were realized in combination with other initiatives. He went on to say:

> So mandatory referral is an absolutely critical element, but you need a DCD program. You need the leading practices around brain death, and you need a DCD program to all be in place. With all of them being in place, you will have really a system firing on all cylinders. And that's exactly what we've seen in BC, Ontario, and Quebec, and Atlantic Canada. [8]

Dr. Fenton referenced a need to educate front-line staff to successfully implement mandatory referral. Ms. Schimpf of the Saskatchewan Transplant Program added that donation physicians are required. She said:

> Mandatory referral, donation physicians are also essential in. They are our collaborators from ICU to ICU. They are knowledgeable. They offer education. They build programs. They do data collection; and they link us with, in particular, our ICUs and our ERs [emergency room] to bring them on board to help us make mandatory referral realistic. [16]

With the current drafting of the regulations for *The Human Tissue Gift Act, 2015*, consultations are set to begin with health regions on how to implement mandatory referrals so that every death or imminent death will be reported to the Saskatchewan Transplant Program. The Saskatoon Health Region is the only health region in Saskatchewan at this time that has policies to support mandatory referral.

Ms. Olson indicated that accountability for results also translates to increased referral. She indicated that Ontario enjoys a 94 per cent referral rate because hospitals are required to report their referral statistics publicly and therefore are held accountable for their performance. [19]

Improving Consent

Saskatchewan currently subscribes to a system whereby willing donors attach a sticker to their health card to indicate their consent to donate. Several presenters believe this is inadequate and contend that other means of registering consent would help to increase the rate of organ donation.

The Kidney Foundation of Canada conducted a study in Alberta to understand the potential for organ donation. According to Ms. VanDeurzen, the study shows a high public willingness to donate, and only 10 to 20 per cent of potential donors are lost due to lack of consent. [17] The remaining 80 to 90 per cent of

missed opportunities are systemic failures that could be fixed within the health care system. [17] She indicated that these statistics are consistent with other jurisdictions surveyed in the US.

Dr. Fenton and Ms. Hubick of The Lung Association of Saskatchewan recommended that the Government of Saskatchewan survey the people to see what the barriers to consent actually are. Withheld consent may be due to cultural or religious reasons, but it may involve other elements. This research may help to develop a more culturally appropriate program.

Obtaining Family Approval

Once a potential donor has been identified, a donor coordinator or other health care professional must approach the family to ask for consent to use the potential donor's organs. If the family does not consent, the organs are not used, regardless of what the potential donor's intent had been regarding organ donation. Ms. Hubick said:

> The current process for organ and tissue donations allows the ability for the next of kin to override a donor sticker placed on a health card. While some do attach an organ donor sticker to their health cards, what matters most is that people are actually able to fulfill their intention to become donors upon their deaths. [20]

Several presenters noted that the biggest barrier to obtaining family consent was that the family was unaware of their loved one's wishes. Dr. Fenton explained what an uninformed family may experience:

> My experience, having worked in intensive care units, is that this conversation's often happening for the very first time for people at a time when it's the worst time in their life. Somebody that they love is dying, and they've never talked about whether they'd want to be an organ donor. They've never really given it much consideration as it applies to their life, and somebody's asking them to come up with some kind of decision today.
>
> You know, this is a time-sensitive thing . . . making important decisions under that kind of stress is just not the right recipe for success. [21]

A majority of presenters identified the need for public awareness campaigns regarding organ donation to help facilitate conversations between family members. When family members are previously made aware of an individual's consent to be an organ donor, they are relieved of the decision-making burden. Many presenters believe public awareness campaigns and the resulting conversations are key to the creation of an organ donation culture in Saskatchewan.

Dr. Fenton and Mr. Richardson of Deloitte indicated that effectively approaching a family to obtain consent requires specialized training. Mr. Richardson noted:

> So there are leading practices on how that's done, what some of that script looks like, who should engage, and how you should engage those families. That makes a big, big difference, converting from approach and consent and then getting increased donation. [22]

Mr. Angus, Ms. Olson, and Mr. Furman pointed out that health care professionals, especially those in rural areas who may know the affected family, don't have the expertise or the emotional ability to approach family. Mr. Furman said:

> You're in a smaller hospital in a smaller community; it's not going to be the easiest discussion to have, to go and engage in a discussion with a family who frankly may be friends of your family. [23]

Donation specialists to train front-line staff, answer questions on how to best approach the family, or be available themselves to provide contact with the family were all suggestions brought to the committee's attention.

As recipients, Ms. Olson and Ms. Duncan have been involved in speaking to groups of front-line staff and thanking them for approaching families about organ donation. They feel it is also important to raise awareness within the health system as to the importance of organ donation.

Presumed Consent

Presumed consent is a system whereby the government presumes everyone has consented to be an organ donor in the event of their death. A presumed consent system often goes hand in hand with an opt-out registry which allows individuals to register refusal of consent to donate.

Spain, Croatia, and Portugal all have presumed consent systems, and they all enjoy donation rates higher than 25 donations per million people. [6] Ms. Olson pointed out that in Austria, presumed consent was introduced in 1982, and by 1990 it had quadrupled its donation rates. [24]

Six presenters recommended the Government of Saskatchewan adopt a presumed consent approach. Five of these presenters relayed personal stories of their journey through the donation and transplantation system. As Mr. Angus said:

> If it was my son or daughter, my mother or father, brother, sister, grandchild, or grandparent were on that transplant list, would I support the opt-out system? I think the answer is clear. [25]

Supporters of presumed consent contend that such a system would take the burden off of a grieving family to decide whether their loved one wanted to donate their organs, and it would also take the burden off health care professionals to approach a family to gain consent. Mr. Furman stated that presumed consent " . . . would provide an easy opening to folks in those types of discussions to maybe more easily engage in the discussion." [23] No time would be lost in attaining consent, and organs could be processed and transplanted more quickly. Mr. Furman also indicated that presumed consent may attract more specialists to Saskatchewan since they will be provided with more opportunity to practice their donation or transplantation specialty.

These presenters believe that the culture of Saskatchewan would support such a system as long as people were offered several avenues to opt out. While Ms. Van Deurzen of the Kidney Foundation of Canada agreed that public support for registries and presumed consent is high, she argued that neither approach has much impact on the rate of organ donation. She said, "We have recently implemented a registry system in Alberta because the public does clamour for it. The public also clamours for presumed consent." [17] She went on to say, "Both of these strategies, these tactics, are based on the premise that consent is the reason why we don't have enough organs to transplant. And that is simply not the case." [17]

Ms. Schimpf of the Saskatchewan Transplant Program said:

> In Spain, a country that has presumed consent, Spain had donor rates in line with the rest of the world, even with presumed consent. It was not until they developed a program that included donor physicians and front-line staff that worked with donor physicians, staff, families to educate, to embrace donation to make it a norm in that country. That is when their donor rates excelled. [16]

Ms. Schimpf also noted that it is common practice, even in jurisdictions with presumed consent, to approach families and try to gain their approval. Mr. Richardson from Deloitte explained:

> It's typically a soft implementation. And what I mean by that is it's kind of counter to medical ethics to just automatically go in and say, this person is brain-dead, therefore let's bring in the team; let's do organ retrieval. There's still that approach and consent. You still approach the family, work through that piece when you're looking for consent from the family. [26]

Several organizations raised concerns with the implementation of a presumed consent system. Ms. Schimpf and Ms. VanDeurzen cautioned that presumed consent may create fear and mistrust with the public. Mr. Wyatt with the Ministry of Health indicated that some countries, such as Brazil, have rescinded their presumed consent legislation. Mr. Richardson indicated that the United Kingdom has decided to stay with an opt-in system and invest money in public awareness to improve consent.

Registries

Registries can either allow those who do not consent to donate their organs to opt out of a presumed consent system or allow willing donors to register to become an organ donor in the event of their death. Alberta, BC, and the Northwest Territories currently have willing donor registries.

Although registries have frequently been noted as an element of successful organ donation programs, several presenters indicated that registries alone have little impact on donation rates. Their effectiveness stems from raising public awareness and facilitating discussion. Mr. Richardson of Deloitte pointed out that registries can also serve as an important tool to gage public engagement and interest in organ donation. Dr. Fenton reiterated, "There isn't a lot of supportive data to suggest that a registry is going to change the game for us, but it's certainly a tool for public awareness." [27]

Several presenters suggested that opt-in registries could collect names of willing donors through institutions serving the public, such as motor license issuers or Revenue Canada. They believe this would be more effective than self-registry methods. Other presenters suggested that an opt-out registry tied to a presumed consent system would be more effective. Ms. Olson stated:

> Statistics have shown that 80 to 90 per cent of Canadians would be willing to donate, but many of them don't take the steps to indicate their wishes. With an opt-out program, you'd better believe that if they're opposed, they're going to take the necessary action to get their name on the list saying that I do not want to donate. [24]

The Information and Privacy Commissioner noted legal implications in collecting registry information. If personal or personal health information was collected through a motor license issuer, each issuer would need to sign an information-sharing agreement with any other agency involved, and each employee would need additional training on how to protect private information. He indicated that as the number of people with access to the information increased, the risk of a breach of privacy would increase as well. It would

also be important to ensure the collecting agency has the mandate to collect the information. Privacy concerns are the same for both opt-in or opt-out registries.

Public Awareness Campaigns

Most presenters stated that the most important message that any public awareness campaign must convey is that individuals should inform their families of their wishes regarding organ donation. Family override to consent occurs primarily because the family is unaware of loved one's wishes. Mr. Furman, Mr. Hofmann, and Ms. Schimpf all suggested that public awareness is vital to forming a culture where organ donation at death was the expectation in Saskatchewan.

Clearing up misconceptions was also mentioned as a goal for public awareness campaigns. A common misconception identified by Ms. Schimpf is that kidneys are the only organ you can donate in Saskatchewan because it is the only organ transplanted in the province. She would like to reassure the public that all organs and tissues donated find a recipient through organ donation organizations. Dr. Fenton and Ms. Hubick noted that some people fear their end-of-life care will differ if they are identified as an organ donor. Dr. Fenton and Ms. Hubic suggested the government survey the public as to perceived barriers to organ donation and identify public misconceptions. This would better target any public awareness campaigns to issues that resonate with the public, and the message could be culturally adapted for different audiences as needed.

Several presenters offered suggestions on how to raise public awareness, such as advertising campaigns, team and corporate sponsorships, fundraising events, branding, and sharing personal stories. Ms. Schimpf noted that public awareness campaigns have been shown to raise rates in the short term, but they need to be consistent to create an organ donation culture in Saskatchewan. Many presenters called upon the government to provide ongoing funding for public awareness campaigns.

Several presenters also indicated that information regarding organ donation in Saskatchewan is difficult to find. A common suggestion was to develop a web page providing information on organ donation and contact information for additional questions. Mr. Hoffman referenced BC Transplant's website, which he felt was a leader in that respect.

The Information and Privacy Commissioner called for communication with the public as to what the Government of Saskatchewan's position is on organ donation. He recommended a policy where, if a program changes, potential donors are kept up to date as to what the changes are.

School Curriculum

Several presenters suggested making organ donation part of the school curriculum. Ms. Duncan referred to the One Life, Many Gifts program that is currently being developed to educate high school students about organ donation, and the Saskatchewan Transplant Program provided a document in response to committee questions regarding this program. The program has been approved for inclusion in the grades 10 and 11 Christian ethics curriculum in Saskatchewan Catholic schools, and it will be reviewed by the Ministry of Education as part of the next curriculum redesign for Saskatchewan public schools. [28]

Improving System Capacity

If the rate of organ donation increases, capacity needs to be built into the system to move donations to the transplant stage. Mr. Richardson indicated that an organ needs to be transplanted between 24 to 48 hours after donation, while certain tissues can store for up to five years. [29]

Several presenters mentioned the need for a culture change within the health care system to support organ donation. Even with rate increases, without this culture change, additional transplants may not materialize. They indicated that adequately resourced support systems need to be in place and staff need to be trained to move donations through the system quickly. Operating rooms need to be made available for transplants as well as for emergencies. They also noted that outcomes need to be measured and evaluated, and accountability needs to be enforced for the system to perform adequately.

Coordination

Several presenters, as noted on page 10, recommended the establishment of a stand-alone organization to oversee organ donation. They believe an organization with a governance structure independent of the health regions could more effectively advocate for and implement consistent programs and processes across Saskatchewan and facilitate co-operation and coordination between the health regions and other stakeholders. Mr. Richardson from Deloitte recognized the need for coordination across health regions, as the implementation of a strong system in only one region is not enough to impact provincial performance. He said:

> Provincial coordination, how is that being looked at across the province? Individual hospitals, you can have a great team, great people, support from leadership; an individual hospital can do great, but when you step back and look at it from a province-wide basis, if that's not happening everywhere, you're going to have ultimately at the end of the day maybe not much movement on that total number of donations happening in province. [30]

Coordination at a national level also means that limited resources are not being spent on research or program development that has already been performed by other jurisdictions. Canadian Blood Services has provided the framework for a strong national system, and Ms. Young suggests that by working with Canadian Blood Services, the provinces can help to create a stronger and more cohesive system across Canada. She said:

> Again, providing professional education, there is much we've learned . . . So our vision is doing it once at the national level around the data, keeping it updated, keeping it current, and then supporting the provincial programs in that implementation, so that every province isn't creating a new education program, but rather they're focused on the delivery of a program that's been done with them collaboratively. [31]

Mr. Richardson noted the need to work in collaboration with all stakeholders involved in the system to improve awareness and implement practices to increase the rate of organ donation in Saskatchewan as well as interjurisdictionally.

Technology

Several presenters discussed technological advancements in donation and transplantation and noted the high cost of purchasing and utilizing new technologies. Dr. Fenton suggested the government provide more funding for bridging technologies to support individuals on life support who are awaiting transplantation, and for machinery that can revive marginal organs so that they are able to be used for transplant. These technologies are available in Edmonton, but there is a cap on the amount they are used due to high cost. He stated, "The way I can see us participating is to contribute to that to expand that cap."[32]

Geography

Several presenters indicated that the distribution of population across a wide geographic area presents barriers to improving the rates of organ donation outside the major centres. Time considerations, lack of organ donation or transplantation expertise in small centres, and travel logistics all play a role.

Coordination with emergency medical services across the province and Shock Trauma Air Rescue Society (STARS) helicopters was noted by several presenters to be a key factor in obtaining organ donations from rural areas. Dr. Fenton suggested that a wide range of options be considered to address geographic constraints, such as evaluating whether it makes more sense for a potential donor to be transferred to the donation team in a large centre, or for the team to meet the donor in a smaller centre.

Performance Measurement and Accountability

Several presenters noted that in order to understand which processes in the system are working well and which areas need to be improved, data must be collected and performance must be measured. Ms. VanDeurzen of the Kidney Foundation stated:

> We need to measure results and create accountability. What gets measured gets done. What gets reviewed, people start feeling accountable for. It's very important. [16]

She added that unless there is clear accountability for performance, improvements to the system are difficult. Clear authority for performance data and quality control across the system must be delegated. Ms. Young of Canadian Blood services stated:

> Deceased donation, the mandatory referral with death audit, the policy's important but the accountability is essential. So if you've got these cases being referred to the program, but no one in senior leadership in the health authority is managing that referral and understanding those missed opportunities, then the policy, like in many other provinces, will lay dormant and not be as effective.[33]

Mr. Richardson of Deloitte noted that coordinating policies across health regions is difficult, but active engagement and collaboration across the system is needed in order to improve the rates of organ donation in Saskatchewan.

Improving Living Donation Rates

Ms. Young and Dr. Nickerson of Canadian Blood Services indicated that potential living donors are lost because it takes too long to move them from assessment and testing to donation. Ms. VanDeurzen of the Kidney Foundation of Canada recommends decreasing the inconvenience to living donors and providing great customer service in order to improve living donation rates. Dr. Nickerson of Canadian Blood Services and Ms. Harris stressed the importance of having pre- and post-operative support and funding available for living donors as well as transplant recipients.

Ms. VanDeurzen, Ms. Harris, and Ms. Hubick from The Lung Association indicated a need to increase public awareness on living donation. They state that information on becoming a living donor in Saskatchewan is difficult to find, and a webpage should be developed to outline the process and resources available. Ms. Schimpf from the Saskatchewan Transplant Program also expressed the need to collaborate more with First Nations and Metis groups because this demographic makes up about half of the people in Saskatchewan who have chronic kidney disease, yet only 15 per cent of them receive a kidney transplant. [34]

Ms. Young of Canadian Blood Services stressed that someone must be assigned the role of advocating for living donation. She said, "It can't be something done on the side of someone's desk. It must be a role that's entrenched and offered for those cases to move forward." [33]

Legislation

The Human Tissue Gift Act, 2015

The Human Tissue Gift Act is the legislation in Saskatchewan that governs the sharing of organ and tissue donation information. As Mr. Wyatt from the Ministry of Health pointed out, the Act's name clearly demonstrates that it views organ and tissue donation as a gift which is given by a donor or consented to by the donor's family. This legislation would not currently support presumed consent.

Regulations for this Act are currently being drafted to include a mandatory referral process, pay for the costs to process and import corneas from other jurisdictions, and coordinate a mandatory referral process across regions. Standard trigger criteria, data collection, and performance monitoring provisions are also being developed.

The Information and Privacy Commissioner proposed an amendment to section 16 of this Act to ensure information collected for an organ and tissue donation program remains private. [35] The amendment would require that organizations wishing to share information with each other must enter into written information-sharing agreements and that these agreements must contain specific provisions.

Mr. Richardson of Deloitte notes that the current Act does not state which organization is going to coordinate organ donation or what the mandate of an organ donation organization would be. The Saskatchewan Transplant Program, Dr. Fenton, and Mr. Richardson would like to see the development of an agency to coordinate organ donation that is independent of health regions and the Saskatchewan Transplant Program.

Mr. Furman urged the government to create a clarity of roles in the legislation for the donors, their families, and the medical team. He would like to see legislation that ensures the wish of the donor is adhered to and is not subject to family override.

The Health Information Protection Act

The Information and Privacy Commissioner has recommended changes to section 27(4) of *The Health Information Protection Act* to give a trustee, without consent, the authority to convey the wish of a deceased person to be an organ donor. [36]

Bill C-223 — *Canadian Organ Donor Registry Act*

Federally, Bill C-223, the *Canadian Organ Donor Registry Act*, was recently defeated. Ms. Harris and Ms. Olson recommend the province lobby the federal government to reconsider legislation to develop a national registry of willing donors.

Summary of Presentations

June 2, 2016 — Regina

Ministry of Health
Hon. Dustin Duncan, Minister of Health
Hon. Greg Ottenbreit, Minister Responsible for Rural and Remote Health
Mark Wyatt, Assistant Deputy Minister
Deborah Jordan, Executive Director, Acute and Emergency Services
Luke Jackiw, Director, Hospital and Specialized Services, Acute and Emergency Services Branch

Mark Wyatt and Deborah Jordan from the Ministry of Health provided information and statistics regarding organ and tissue donation in Saskatchewan and in other jurisdictions. They outlined the key components of organ donation systems with high donation rates and recommended that each component be studied to see how it would apply in the Saskatchewan context. They cautioned that the implementation of one component does not necessarily translate to improvements in donation rates, and initiatives such as registries or presumed consent may register little impact.

Mr. Wyatt and Ms. Jordan identified some of the initiatives that Saskatchewan is currently undertaking in order to improve its organ and tissue donation system. Regulations corresponding to The Human Tissue Gift Act, 2014 are currently being drafted. Mandatory referral of potential donors to organ donor coordinators, allowance for payments to be made to other jurisdictions for the cost of processing or importing a cornea, and the development and monitoring of performance indicators will be addressed in the regulations.

Saskatoon Health Region is currently revising the criteria used to identify potential donors to include donations after cardiocirculatory death. Expansion of this program will have a positive impact on organ and tissue donation rates. Improving coordination between regional hospitals, increasing donation by seniors, facilitating public awareness, and identifying missed opportunities were suggested as potential focus areas.

September 6, 2016 — Regina

Charlotte L'Oste-Brown

Charlotte L'Oste-Brown was diagnosed with pulmonary fibrosis in 2003 and was placed on the lung transplant list in 2014. She shared her story with committee members, touching on her physical decline, financial hardships faced, and mental anguish. She contends that long wait times prior to a transplant can result in patients feeling hopeless and contemplating suicide.

Ms. L'Oste-Brown recommends the development of an organ donor consent registry which could be administered by institutions already collecting personal information, such as Crown corporations, banks, or doctor's offices. She also recommends undertaking public awareness campaigns and developing educational programs to dispel myths, reinforce the importance of organ and tissue donation, and encourage conversation.

Office of the Saskatchewan Information and Privacy Commissioner
Ronald J. Kruzeniski, Saskatchewan Information and Privacy Commissioner
Diane Aldridge, Director of Compliance

Ronald J. Kruzeniski and Diane Aldridge outlined considerations related to the collection, use, and disclosure of personal information and personal health information, the maintenance and storage of this information, and key elements of information-sharing agreements. To ensure information collected in any future organ and tissue donation program remains private, the Office of the Saskatchewan Information and Privacy Commissioner recommended an amendment to section 16 of The Human Tissue Gift Act, 2015 stipulating that organizations wishing to share information with each other must enter into written information-sharing agreements. Any such agreement would outline:

- The purpose for collecting, using, or disclosing the information
- Prohibitions for the collection, use, or disclosure of the information for any purposes not listed
- The obligations of each party to safeguard the information
- A requirement that each party comply with other relevant Saskatchewan legislation
- A requirement to report any breach of privacy or any conditions of the agreement that have been broken
- The actions to be taken in the event of a breach
- The means to terminate the agreement while still ensuring the security of the information
- Allowance for the organization sending the information to audit the organization receiving the information to ensure it is complying with the agreement

Mr. Kruzeniski pointed out that both opt-in and opt-out programs are a concern to privacy because both involve the collection, use, and disclosure of personal health information. He stated that third-party information collection, such as through driver's licence issuers, would require a separate information-sharing agreement for each agency, and all staff would need additional training. Access should be controlled and the information system activity monitored. Since the risk of a privacy breach increases as the number of employees with access to the information increases, he asked that if the committee wishes to move forward in this manner, he be given the opportunity to reflect further on legislative changes and make further recommendations

He also recommended changes to section 27(4) of The Health Information Privacy Act to give a trustee, without consent, the authority to convey the wishes that a deceased person wants to be an organ donor. He asked that the committee recommend this to the Legislative Assembly in its report.

Lastly, he recommended continuous communication with the public as to what the government's policies are on organ donation and advising of any changes to the program.

September 7, 2016 — Regina

Cory J. Furman
Tammy Furman

Cory J. Furman and Tammy Furman have been actively involved in increasing public awareness about organ donation since Ms. Furman had a liver transplant in Hawaii in 2010. They believe that had Ms. Furman been diagnosed in Saskatchewan, she would have died due to the low donation rates. Lack of

technical expertise within regional hospitals, geographic distance from surgical centres, and the emotional burden faced by medical staff in small centres in facilitating conversations with potential donor families were identified as causes. The Furmans believe a presumed consent system and an increased focus on identifying and referring potential donors, including cardiac death donors, would help to alleviate some of these issues. They believe the culture currently would support an opt-out system as long as it was easy for people to opt out and multiple channels were made available to do so.

The Furmans would also would like to see a process implemented whereby a transplant recipient can send a letter, via the hospital, to thank a donor family.

September 12, 2016 — Saskatoon

Fred Hofmann

Fred Hofmann, a transplant recipient, recommended a presumed consent system whereby opt-out requests were registered through driver's license issuers and linked to electronic health records. He stressed the importance of expanding technical capabilities in Saskatchewan hospitals, information sharing between organizations and provinces, and early identification of potential donors. He offered numerous suggestions on how to raise public awareness with regard to organ donation, including a comprehensive advertising campaign and educational programs in the schools. As the British Columbia rate of donation is the highest in Canada at 22 per cent, Mr. Hofmann provided samples from their public awareness materials that Saskatchewan may find useful in developing their own template.

Saskatchewan Transplant Program
Erin Schimpf, Provincial Program Manager, Saskatchewan Transplant Program
Dr. Gavin Beck, Transplant Surgeon, Surgical Co-lead, Saskatchewan Transplant Program
Dr. Rahul Mainra, Transplant Nephrologist
Dr. Mike Moser, Transplant Surgeon

In Saskatchewan, the Saskatchewan Transplant Program supports organ and tissue donation as well as oversees transplantation. It is governed by the Saskatoon Health Region; however, one of its two offices is the Kidney Health Centre, which is governed by the Regina Qu'Appelle Health Region. The perceived conflict of interest between transplantation and donation, a lack of resources, and an unclear governance structure make collaboration between health regions and the implementation of changes to improve the rate of organ and tissue donation difficult. The Saskatchewan Transplant Program recommended that a separate organ donation organization be established and donor physicians be hired to support the donation side so that important changes can be implemented.

Key changes, as identified by STP, include mandatory referral of all deaths or imminent deaths to STP and the implementation of a DCD program. While progress on these fronts is currently being made in Saskatchewan, STP maintains that donor physicians are necessary to provide the advocacy, education, and technical support to front-line staff and other stakeholders to implement these programs. Changing the culture within the health care system to one where organ and tissue donation is front and centre is imperative to a successful organ and tissue donation program (STP and Ms. Young CBS)

STP also recommended a funding increase for ongoing public awareness campaigns to change Saskatchewan's culture to one where organ donation is the norm. Improved collaboration with First Nations and Metis organizations is also important because these people make up half of all people needing kidney transplant but only receive 15 per cent of the transplants.

Canadian Blood Services
Kimberly Young, Director of Donation and Transplantation
Dr. Peter Nickerson, Kidney Transplant Specialist, Medical Advisor for Donation and Transplantation

Canadian Blood Services is the national leader and coordinator of organ and tissue donation in Canada. They operate the Canadian Transplant Registry, which links people awaiting a transplant to donated organs, and the kidney paired donation program in which a living donor donates a kidney to the network in return for a match being made for their loved one. They develop policies and best practices, conduct research, provide education, and collect, maintain and monitor system performance data from partner jurisdictions across the country.

Canada's organ donation rates have risen 29 per cent since 2006. CBS attributes this primarily to DCD programs. While DCD programs, mandatory referral, donation physicians, and implementation of best practices around determination of brain death all play a role in increasing organ donation rates, they do not produce results alone. Supports within the system to manage referrals, understand missed opportunities, and maintain accountability of programs are needed for a successful organ and tissue donation system.

Canadian Blood Services indicated that it would be more cost effective for Saskatchewan to change its focus of end-stage kidney disease treatment from dialysis to kidney transplant. To change this focus, capacity must be built into the system to ensure that assessment and donation can occur quickly so living donors are not lost. Adequate support of donors and their families, before and after transplant, is also necessary.

Cheryl Olson

Cheryl Olson has received two heart transplants, both from young donors. She suggested several avenues to raise public awareness on the importance of organ donation, including educating youth through the schools as well as professionals in the health care system. She also touched on mandatory reporting and suggested that publishing the statistics regarding the reporting from hospitals would keep them accountable. Like several other presenters, she keyed in on creating a culture change where organ donation becomes the norm. Ms. Olson believes a presumed consent system would be more effective than an opt-in system because people may not take the action required to opt into a registry.

Twyla Harris
Carmen Harris
Rosalyn Harris

Due to a genetic condition affecting bone marrow and the respiratory system, several members of the Harris family have required a transplant. In memory of an aunt who passed away, they have helped to establish the Karen Pilon Organ Donor Awareness Foundation which raises funds to increase public awareness, buy equipment, and provide financial support to people awaiting a transplant. The Harris

family recommends the Saskatchewan government undertake a broad public awareness campaign to stress the importance of organ donation, remove barriers to donation by gay men, build organ donation education into the grade 8 science curriculum, and provide more information and financial support to encourage living donation. They would like to see the immediate implementation of an online registry of willing donors while the government undertakes the groundwork necessary to create a presumed consent system.

The Lung Association of Saskatchewan
Jill Hubick, Registered Nurse and Certified Respiratory Educator
Charlotte L'Oste-Brown
Nicole Nelson

Jill Hubick provided an overview of the systems in place for lung transplant recipients in Saskatchewan. Lung transplants are not performed in Saskatchewan, so in the months surrounding a transplant, most of a recipient's medical care is provided out of province. Charitable organizations help to cover the costs of the transplant recipient's travel, accommodation, and food, but recipients and their support people face many more out-of-pocket expenses. Charlotte L'Oste-Brown and Nicole Nelson relayed their personal experiences navigating these systems.

They believe a culture shift in Saskatchewan is necessary to make organ donation a norm. To achieve this, they recommend that the government allocate funds to increase public awareness; provide education in the schools; build capacity in the system to identify potential donors, medically manage donors, and investigate lost opportunities; and provide additional resources to recipients and their support people such as affordable housing, child and pet care costs, and supplements for lost wages.

Mark Fenton

Dr. Mark Fenton established a clinic in Saskatchewan in 2008 to take over the care of patients who have received a lung transplant out of province. People die waiting for a transplant because of a lack of available donors. He made several recommendations that he believes will help to improve the donation rates.

First, he advises surveying the public to find out why families do not consent to a deceased loved one's donation. He believes that an opt-out system and public awareness to address identified barriers will help.

Within the system, he recommends utilizing donor specialists to champion and implement a DCD program and provide education and training to front-line staff to facilitate referrals. He also recommends that all transplant funding be independent of regional health authorities' funding, and dedicated funding needs to be set aside for an organ donor organization within the province. With mandatory referrals, Dr. Fenton stresses the importance of investigating how best to operationalize the system to reach donors in tertiary centres.

Dr. Fenton also recommends increased funding for bridging technologies to support people as they wait for a transplant and supporting out-of-province technology to resuscitate marginal donor organs so they can be used. There are caps on the amount expensive technologies are used, and if Saskatchewan helps to pay its part, the cap can be raised.

Jim Angus

Jim Angus received a liver transplant in 2006. He believes that most rural hospitals don't have the skills and training to deal with families in times of grief and the message isn't getting through to people in urban centres either. In addition, during the chaos of an accident, checking a health card to see if the organ donor sticker has been applied isn't considered. He believes a presumed consent system would rectify this problem. More organs would be available for transplant, the burden would be removed from family to make such an important decision at a time of stress, and the burden would be removed from health care professionals to counsel families in regard to organ donation at a difficult time.

September 13, 2016 — Saskatoon

Deloitte
James Richardson, Senior Manager, Public Sector Transformation

Mr. Richardson provided a process map of the 17 functions of a highly effective organ and tissue donation system and outlined the functions within three levels: front-line service delivery focusing on the donor, donor family, and recipient; enabling supports to front-line service delivery; and system supports focused on efficiency, coordination and systemic improvement. Jurisdictions with high rates of organ donation have some degree of stand-alone organ donation organization, donor coordinators, and clinical leads (i.e. donor physicians).

He pointed out that a systemic approach is needed to improve the rate of organ and tissue donation, and improvement in one area or the implementation of one component of an effective system will not lead to results. Mr. Richardson's first recommendation is to establish a stand-alone organ donation organization in the province. Then, of the 17 functions mapped, he recommends the Government of Saskatchewan focus on improving identification and referral and approach and consent at the front-line level; ensure hospital engagement and provincial coordination at the enabling-support level; and implement performance management measures, quality assurance, strong information management and IT programs, and ensure legislation and provincial policy supports the system as it should.

The Kidney Foundation of Canada, Saskatchewan Branch
Joyce VanDeurzen, Executive Director

Joyce VanDeurzen indicated that 75 to 80 per cent of the people on a waiting list for an organ transplant in Canada are waiting for a kidney, and a transplant can more than double a person's life expectancy. Resources spent on transplants will more than pay for themselves in terms of cost savings to the health system and future tax revenues from employed recipients.

The Kidney Foundation is not advocating for presumed consent or a registry; this assumes that low donation rates are due to consent, and studies have shown that only 10 to 20 per cent of potential donor organs not recovered are due to lack of consent. The other 80 to 90 per cent are lost because potential donors are not being identified and brought forward in the system. Ms. Van Deurzen recommends implementing mandatory referral, donor specialist teams, and DCD programs to increase the rates of donation from deceased donors. She also recommends removing barriers to living donation by educating the public, reducing the time period from assessment to match, and providing living donors the best

possible customer service. Ms. Van Deurzen also stressed the importance of building accountability into performance outcomes.

Sherry Duncan

Sherry Duncan relayed her personal experience leading up to a heart-lung transplant 25 years ago. She is an advocate for presumed consent, which will take the decision-making burden off of families, but believes education is much more important. To create a culture that identifies and brings forward potential donors, she believes that educating organ donation teams in ICUs is imperative. In terms of public awareness, she referenced the One Life Many Gifts curriculum development between Saskatchewan Transplant Program and the Catholic School System to build organ donation into the Catholic school curriculum in grades 10 and 11 Christian ethics. She believes that stories relayed by donor families and by transplant recipients are important in both cases to put a real face to people who are impacted by organ donation.

Summary of Written Submissions

Nine individuals and one organization provided the committee with written submissions. Five submissions recommended an opt-out or presumed consent system, and two additional submissions called for a registry. Suggestions as to how to collect consent information included an online registry, a checkbox on the income tax form, and a survey by family doctors. Several submissions suggested that willingness to consent be linked to an individual's electronic health record.

Education and public awareness were recurring themes. The need to educate the public on how important organ donation is and for people to speak to their families about their wishes was indicated in over half of the submissions. Ms. Wedhorn recommended that the public be reassured that end-of-life care will not be diminished if one is identified as an organ donor. Suggested avenues to increase public awareness included advertising, public speaking by those impacted by organ donation, trade show kiosks, and information distributed by family doctors.

Ensuring capacity in the system to support increased organ donation was also recognized. Mr. Pannell and Ms. Kurysh recommended that donor physicians be utilized to educate the medical community and help to implement new initiatives such as mandatory referral and DCD programs. The Canadian Transplant Program suggested that a 24-hour call line be established to answer questions on organ donation and provide information and support to both the public and the medical community.

Recommendations

After considering all testimony and written submissions, the committee makes 10 recommendations.

Recommendation 1

Your committee recommends the development and implementation of public education and awareness campaigns aimed at increasing knowledge about the importance of organ and tissue donation, both living and deceased, among the general public.

Recommendation 2

Your committee recommends the development and implementation of educational programs aimed at increasing the knowledge among the health care professionals of how to identify potential donors and how to approach the family to gain consent for organ and tissue donation.

Recommendation 3

Your committee recommends the development and implementation of educational programs aimed at increasing knowledge of the importance of organ and tissue donation among primary and secondary school students.

Recommendation 4

Your committee understands that a presumed consent system for organ and tissue donation has not been implemented in any jurisdiction in Canada, and that implementation of such a system would likely be challenged in the courts. Given this, your committee recommends the continued use of an enhanced opt-in system of consent for organ and tissue donation. Your committee further recommends the creation of an intent-to-donate registry for both living and deceased organ and tissue donation, with SGI collecting information from those who intend to donate and with health care professionals able to access the registry via e-health.

Recommendation 5

Your committee recommends that the Ministry of Health examine the use of donation physicians in other jurisdictions and establish a donation liaison position to bridge the gap between intensive care teams and organ and tissue procurement teams, utilizing whatever professionals are most appropriate, with the aim of improving leadership, advocacy, training and education within the system.

Recommendation 6

Your committee recommends that donation after cardiocirculatory death (DCD) be fully included as an acceptable source of organ and tissue donation in Saskatchewan.

Recommendation 7

Your committee recommends the Ministry of Health continue to provide funding for organ and tissue donation to improve donation rates in Saskatchewan.

Recommendation 8

Your committee recommends the Ministry of Health create targets, determine appropriate performance indicators and accountability measures, and ensure thorough data collection in regards to organ and tissue donation.

Recommendation 9

Your committee recommends a review of organ and tissue donation rates be conducted after two years of implementation of the committee's recommendations to determine if additional measures ought to be taken to further increase the rate of organ and tissue donation in Saskatchewan.

Recommendation 10

Your committee recommends enhancing public education, peer support, and professional education around living donation and supports the reduction of barriers for the living donor and the recipient.

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[15] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at p. 282 (Ms. Duncan)
[16] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 232 (Ms. Schimpf)
[17] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at p. 277 (Ms. VanDeurzen)
[18] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 243 (Ms. Young)
[19] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 247 (Ms. Olson)
[20] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 256 (Ms. Hubick)
[21] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at pp. 259-60 (Mr. Fenton)
[22] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at pp. 270-71 (Mr. Richardson)
[23] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 12*, 28th Leg, 1st Sess (7 September 2016) at p. 218 (Mr. Furman)
[24] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 248 (Ms. Olson)
[25] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 266 (Mr. Angus)
[26] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at p. 273 (Mr. Richardson)
[27] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 260 (Mr. Fenton)

[28] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at p. 282 (Ms. Duncan)
[29] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at p. 269 (Mr. Richardson)
[30] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 14*, 28th Leg, 1st Sess (13 September 2016) at p. 270 (Mr. Richardson)
[31] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 239 (Ms. Young)
[32] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 261 (Mr. Fenton)
[33] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 242 (Ms. Young)
[34] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 13*, 28th Leg, 1st Sess (12 September 2016) at p. 234 (Ms. Schimpf)
[35] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 11*, 28th Leg, 1st Sess (6 September 2016) at p. 212 (Mr. Kruzeniski)
[36] Saskatchewan, Legislative Assembly, Standing Committee on Human Services, *Hansard Verbatim Report No. 11*, 28th Leg, 1st Sess (6 September 2016) at p. 213 (Mr. Kruzeniski)

Appendix 1: List of Presenters

Ministry of Health
Hon. Dustin Duncan, Minister of Health
Hon. Greg Ottenbreit, Minister Responsible for Rural and Remote Health
Mark Wyatt, Assistant Deputy Minister
Deborah Jordan, Executive Director, Acute and Emergency Services
Luke Jackiw, Director, Hospital and Specialized Services, Acute and Emergency Services Branch

Saskatchewan Transplant Program
Erin Schimpf, Provincial Program Manager, Saskatchewan Transplant Program
Dr. Gavin Beck, Transplant Surgeon, Surgical Co-lead, Saskatchewan Transplant Program
Dr. Rahul Mainra, Transplant Nephrologist
Dr. Mike Moser, Transplant Surgeon

Office of the Saskatchewan Information and Privacy Commissioner
Ronald J. Kruzeniski, Saskatchewan Information and Privacy Commissioner
Diane Aldridge, Director of Compliance

The Kidney Foundation of Canada, Saskatchewan Branch
Joyce VanDeurzen, Executive Director

Deloitte
James Richardson, Senior Manager, Public Sector Transformation***

The Lung Association of Saskatchewan
Jill Hubick, Registered Nurse and Certified Respiratory Educator
Charlotte L'Oste-Brown
Nicole Nelson

Canadian Blood Services
Kimberly Young, Director of Donation and Transplantation
Dr. Peter Nickerson, Kidney Transplant Specialist, Medical Advisor for Donation and Transplantation

Private Citizens

Charlotte L'Oste-Brown

Cory J. Furman and Tammy Furman

Fred Hofmann

Sherry Duncan

Jim Angus

Mark Fenton

Twyla Harris, Carmen Harris, and Rosalyn Harris

Cheryl Olson

Appendix 2: Documents Received by the Committee

Written Submissions

HUS 1-28	Ministry of Health: Presentation on organ and tissue donation, dated June 2, 2016
HUS 8-28	Jerome Cardiff: Submission re: organ donation inquiry, dated August 20, 2016
HUS 9-28	Ronda Wedhorn: Submission re: organ donation inquiry, dated August 22, 2016
HUS 11-28	Charlotte L'Oste-Brown: Submission re: organ donation inquiry
HUS 12-28	Saskatchewan Information and Privacy Commissioner: Submission re: organ donation inquiry
HUS 13-28	Cory J. Furman: Submission re: organ donation inquiry
HUS 14-28	Alex Taylor: Submission re: organ donation inquiry, dated September 7, 2016
HUS 15-28	Robert Pannell: Submission re: organ donation inquiry, dated September 9, 2016
HUS 16-28	Bridget Kurysh: Submission re: organ donation inquiry, dated September 12, 2016
HUS 17-28	Rosalyn Harris: Submission re: organ donation inquiry, dated September 11, 2016
HUS 18-28	Fred Hofmann: Submission re: organ donation inquiry
HUS 19-28	Saskatchewan Transplant Program: Submission re: organ donation inquiry
HUS 20-28	Sharon Melnyk: Submission re: organ donation inquiry, dated September 12, 2016
HUS 21-28	Canadian Blood Services: Submission re: organ donation inquiry
HUS 22-28	Cheryl Olson: Submission re: organ donation inquiry
HUS 23-28	Twyla Harris: Submission re: organ donation inquiry
HUS 24-28	The Lung Association of Saskatchewan: Submission re: organ donation inquiry
HUS 25-28	Mark Fenton: Submission re: organ donation inquiry
HUS 26-28	Jim Angus: Submission re: organ donation inquiry
HUS 27-28	Deloitte: Submission re: organ donation inquiry
HUS 28-28	Corrine Pankewich: Submission re: organ donation inquiry, dated September 12, 2016
HUS 29-28	Sherry Duncan: Submission re: organ donation inquiry

Responses to Follow-up Questions

Appendix 3: Dissenting Opinion

In the spring of 2016, the Standing Committee on Human Services was tasked with reviewing organ donation in Saskatchewan and generating evidenced-based solutions to present back to the legislative assembly. On several recommendations, the committee could not reach consensus, and therefore they were excluded from the report. To appropriately seize the opportunity for meaningful change, opposition members are including the recommendations below, to create a comprehensive strategy for addressing low organ donation rates in Saskatchewan.

Saskatchewan's rate of organ donation is incredibly low, and lags significantly behind other provinces. The average rate of deceased donation in Canada is 17 donors/million people, whereas, in Saskatchewan, that rate is only 8.8 donors/million people.

The committee heard testimony from various stakeholders and reviewed high performing jurisdictions with rates all above the Canadian average, such as Nova Scotia, Ontario, Quebec, and British Columbia.

Testimony was heard from:

- Local officials with an understanding of Saskatchewan's current practices, challenges, and opportunities;
- Organizations who work directly with organ donation, and would be considered experts in the field;
- Organizations who work indirectly with organ donation, but whose work is directly impacts, and is impacted by, organ donation; and
- Saskatchewan people who had experienced transplants themselves or with loved ones.

These intimate stories were entrusted to us, so that we could work to bring change in Saskatchewan and improve the organ donation system for those suffering in Saskatchewan.

One stakeholder urged the committee to consider whether members were seeking incremental or transformative change. With such low organ donation rates, opposition members of the committee believed that the work of the committee, particularly in terms of the report's recommendations, should be as comprehensive as possible.

Recommendations

In addition to consensus on several recommendations (1,7,8,9,10), opposition members of the committee wish to put forward the following recommendations:

Recommendation 1

Opposition members recommend that the Government, working with stakeholders, create legislation, and provide adequate funding for a stand-alone province-wide organ donation organization to ensure the clear separation of interests between the donation process and the transplant process.

- Many high-performing jurisdictions have separate organizations for organ donation and organ transplant. The distinct separation eliminates the inherent conflict of interest of working with both donors and recipients.

Recommendation 2

Opposition members recommend that, in collaboration with stakeholders, government improve the governance structure of the Saskatchewan Transplant Program and create a province-wide authority for the program that is properly resourced and accountable to the people of Saskatchewan.

- Currently, the Transplant program is administered by the Saskatoon Health Region. The current governance structure of the program, within one health region, is incongruent with the services and responsibilities that a Saskatchewan transplant program has to deliver services to the entire province of Saskatchewan.

Recommendation 3

Opposition members recommend that the government create and fund two part-time donor physician positions - one in Saskatoon and one in Regina - to be tasked with building a made-in-Saskatchewan donor physician program to ensure, in time, there are donor physicians across the province.

- Donor physicians are an integral part of high-performing organ donation systems. They have the expertise necessary to identify and work directly with potential donors, their families, and the health care system. Donor physicians work with their colleagues to ensure all opportunities for donation are identified. They are integral to developing the structures and culture within the health care system needed to facilitate increasing organ donation rates. This has been an ongoing request of the Saskatchewan Transplant Program.

Recommendation 4

Opposition members recommend building on the work of the Saskatoon Health Region's donation after cardiocirculatory death (DCD) program, and expand the program to every region of the province, with the support of donor physicians.

DCD programs expand potential donor criteria to include people whose hearts will stop beating with the cessation of life support. A DCD program would include the necessary policies and supports to implement this new donation criterion. The efficiency of a DCD program relies on the presence of donor physicians.

Recommendation 5

Opposition members recommend working, with the support of the two new donor physicians, to expand mandatory referral beyond the Saskatoon Health Region so that all potential donors would be identified and referred to the newly established organ donation organization.

Mandatory referral of all deaths or imminent deaths to the organ transplant program has shown success in some jurisdictions. However, it is cautioned that these successes were realized in combination with other initiatives, and for the best results should be implemented alongside donor physicians and DCD programs.

Recommendation 6

Opposition members recommend improving education for front-line staff and physicians – all those who work directly with patients – in order to foster a culture where organ and tissue donation is accepted as normal practice.

- Enhanced and additional education for front-line staff will build capacity in the system, and can serve to increase identification of all valid donors.

Recommendation 7

Opposition members recommend the inclusion of organ donation as a mandatory topic of the high school curriculum in Saskatchewan in order to foster a culture among the general public where organ and tissue donation is accepted as normal practice.

- Public awareness campaigns can assist in generating increased rates of consent, and making organ donation a part of the school curriculum was suggested to the committee. A program titled, One Life, Many Gifts is currently being developed to educate high school students about organ donation in Greater Saskatoon Catholic Schools.

Recommendation 8

Opposition members recommend the government engage and collaborate with First Nations and Metis communities to improve equity in donations, as well as improve prevention efforts to ultimately reduce the number of transplants needed.

Indigenous citizens make up 50 per cent of those who suffer from kidney disease, but account for only 15 per cent of those who receive a transplant.