STANDING COMMITTEE ON HUMAN SERVICES

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STANDING COMMITTEE ON HUMAN SERVICES

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Published under the authority of The Hon. Corey Tochor, Speaker

Public Hearings: Improving Organ and Tissue Donation Rates in Saskatchewan

[The committee met at 09:49.]

The Chair: — Good morning everyone. Welcome to the Standing Committee on Human Services. I'm Greg Lawrence, the Chair of the committee. First thing, I'd like to introduce the other members of the committee who are here today. We have Mr. Docherty. We have Ms. Chartier. We have Ms. Lambert, Ms. Carr, Ms. Rancourt, Mr. Olauson, and Mr. Weekes.

Before we begin, I'd like to table the following documents: HUS 14-28, Alex Taylor: Submission regarding organ donation inquiry, dated September 7, 2016; HUS 15-28, Robert Pannell: Submission regarding organ donation inquiry, dated September 9, 2016; HUS 16-28, Bridget Kurysh: Submission regarding organ donation inquiry; HUS 17-28, Rosalyn Harris: Submission regarding organ donation inquiry. And that's dated today; those are both dated today.

Today we are continuing our public hearings on how the Government of Saskatchewan can increase the organ donation, the rate of organ donation, and improve the effectiveness of the organ and tissue donation program here in Saskatchewan.

I would like to advise the media and general public of decorum to be followed while in the committee meeting. The public and media are invited to attend the public proceedings, based on seating availability. Photography, videotaping, or recording is not permitted while the committee is meeting. The media may access the audio proceedings from the audio box provided. Any media interviews shell be held outside the committee room, and footage of the committee may be taken before and after committee meetings.

The committee proceedings will be live-streamed on the Legislative Assembly of Saskatchewan website and archived video of proceedings will be available. The committee's website can be accessed by going to the Legislative Assembly of Saskatchewan website at www.legassembly.sk.ca. Public documents and other information pertaining to the hearings are also posted to the committee's web page.

Our first presenter this morning is Mr. Fred Hofmann. I'd like to welcome you to the committee today. Before you begin your presentation, please introduce yourself and anyone else that may be presenting with you. If you are speaking on behalf of an organization, please state your position within the organization represented. If you have a written submission, please advise whether or not you would like to table the submission. Once this occurs, your submission will be available to the public. Electronic copies of tabled submissions will be available on the committee's website.

Once your presentation is completed, the committee members may have questions for you. I will direct the questions and recognize each member that is to speak. Members are not permitted to engage witnesses in any debate, and witnesses are not to ask any questions of the committee.

Our agenda allows for a 30-minute presentation followed by a 15-minute question-and-answer period. And, sir, if you would please proceed now with your presentation.

Presenter: Fred Hofmann

Mr. Hofmann: — Good morning, Mr. Chairman, hon. members of the committee, and guests in the gallery. My name is Fred Hofmann. I am from Warman. Fourteen months ago to the day, to the hour, I was in Edmonton at the University of Alberta Hospital getting a full liver transplant. If it wouldn't have been for that transplant, I'd be dead today.

It started off with the cancer treatments, having the local doctors remove 35 per cent of my liver, and then to keep me alive with the cancer treatments, with the chemotherapy and radiofrequency therapy. And then they got me on to the qualifying list in Edmonton where I went and spent one week. Because of the shortage of organs, you literally are in a contest with everybody else. Of the 21 of us that were there, there was only two of us accepted to be put on the transplant list. So as some of your other presenters have noted, you then get back home and you wait.

At that time you also have to get all your affairs in order because the chance of not getting the organ is greater than actually getting the transplant. So you have to make sure your will is done up, your health directive is done. And after that, you continue waiting, and it is very frustrating. You're told by the surgical teams in Edmonton that you could have one, two dry runs before you actually get your transplant. You then get your call. Mine came at a quarter to four in the morning from Edmonton saying that the person had died in a car accident and it's a match. Do you want the liver? Of course you don't say no.

I was fortunate. I also signed up when I was in Edmonton to be part of a guinea pig project that Dr. Shapiro brought in a warm liver machine out of Great Britain. I was the third person to get a liver that was kept alive in this machine. That way I didn't . . . We were ready for the call to be flown with air ambulance. I drove, probably wasn't the greatest of ideas, but just from that alone, the money that it saves the health system that you don't have to have the cost of an air ambulance.

So obviously the transplant went well. The liver was a good fit. I did crash after 12 hours after the operation, picked up a bug in the operating room, and it went quite badly. I was in ICU [intensive care unit] on life support for five days and on maximum life support for three days. But with the excellent care of the doctor team there, pulled through. Then with others, like with the liver transplants, you have to spend three months in Edmonton for rehab and adjusting of the anti-rejection drugs. Again a huge cost to the health system.

Once you get home, you then have the follow-up with the doctors here to make sure you have blood tests weekly, bi-weekly, that they make sure that the anti-rejection drugs are working properly. So after I went through all that, it's time to give back. So sitting on both sides of the fence, you have a lot of time to see where things can improve.

So the Premier in his Throne Speech acknowledged the problem that in this province we have less than 1 per cent of our population as registered donors, the worst in Canada. And that's pretty bad in a province that comes together for many, many things. We raised millions in Telemiracle building community halls, skating rinks. If a farmer can't get his crop off, his neighbours help him. So why? Why is our rate so low? So I'll present some ideas and suggestions and then, if required, you should have my written submission. It is very, very long, and this is condensed. If you do have questions afterwards and there isn't time, feel free to get in contact with me.

So a donor is known as a hero. And a hero is defined as a person of courageous acts, nobility of character; a person who in the opinion of others has special achievements, abilities, or personal qualities, and is regarded as a role model or ideal. I think that we should refer to the people who are on the list as heroes.

So one of my thoughts and ideas is let's adopt a new logo — something bold, something different. On your handouts and on the little pieces of paper that I gave you was just a suggestion on what the new logo could look like: replace the current little red dot, incorporating the green transplant ribbon along with our prairie lily to signify Saskatchewan, as well as the word "hero."

[10:00]

Most people that I've talked to indicate to me that the sticker itself should be on the driver's licence. You could register and cross-reference to both health cards and driver's licences. Using the new sticker on a driver's licence, you could put it on the back side underneath all the bar-codings and numbers on it. And on your health card, you can see there's quite a different between a logo you could use and that little red dot.

While the current stand-alone link to the Saskatoon Health Region is a good website with information, I haven't found very many people that are aware of that it exists, nor how to access the same. If you go to inquire, do a search, you end up . . . There's a number of dead links, and it's not very user-friendly. Also there is currently no online capability where people can register as donors. Registration should be available online with a follow-up acknowledgement to the family of the donor by letter or by online.

Something that I haven't been able to figure out is why a family can veto a donor's request, even if it's on a signed health directive with a do not resuscitate. So it seems strange that you can have a do not resuscitate request and that will be followed through on, but if you decide that you want to donate your organs, your family can say no. Saskatchewan is the only province that is set up that way. So again something that can be looked into.

You could register with the new eHealth system that is through SGI [Saskatchewan Government Insurance] with driver's licences. Again, establish a prominent, in-depth website, both informational and user-friendly. The handouts that I had sent out from both British Columbia and Alberta are very informative and include all kinds of documentation on transplants and development. Also look at web pages for Twitter, Facebook, as we've become more of an online society.

BC [British Columbia], in your handouts, they had a news release. They're doing some pretty good things. It showed they have a population of 4.6 million. They have just crossed in June this year to one million, twenty-one thousand registered donors. That's 22 per cent of their population. That's pretty incredible. Saturday night on the CTV [Canadian Television Network Ltd.] news it was also noted that by far they have done the best work in Canada. So if your committee is interested, why not send a couple of people to BC and find out why they are doing so well.

So again from the handouts, just a bit of a design change that's a little more eye catching than the red dot.

How do you get more information to the public? Set up some information, trade-style booths in shopping malls, the local co-op store. These would be easily funded by corporate sponsorship. I have talked to some companies and they would be more than happy. This fits right into their community profile. So start off with two and then increase to four. These could be manned by volunteers from the Canadian Transplant Association, various other organizations — heart, kidney, lung, liver, CNIB [Canadian National Institute for the Blind], even some of the service clubs throughout the province.

On the BC website they have set up — and I will leave this for you after, Mr. Chairman — they were more than happy to send out their corporate kits that they use, that they send to corporations that are looking at holding information sessions for their employees, and it includes everything from a T-shirt and pens, tablecloths, along with posters and that type of thing.

Maybe look at a TV ad, similar to the SGI crash video that is out. That is a very good video. Could be just a 30-second narrated infomercial. Look at funding from Sask Health or use the BC video that they had made up, broadcast at Christmastime when everybody's home and finished their meal. Usually if you note, there is no news broadcast and they scramble to look for something to fill in that one hour. At that time you could maybe have some sort of video playing in the background, when families are together, that talks about organ donation.

I believe . . . and I think you're hearing from The Kidney Foundation later today. They have got a video starting up. I think it's called something . . . road to success or something along that line.

Look at decals or bumper stickers on all provincial vehicles, including CVA [central vehicle agency] vehicles, SaskPower, SaskTel, SaskEnergy, with one of these type decals on it, Be a Hero. Very cheap advertising. Get on board with some of our provincial teams with a patch on their jerseys. In the SJHL [Saskatchewan Junior Hockey League], WHL [Western Hockey League], Saskatchewan Rush, having game nights promoting Be a Hero with their players and their fans. Lapel pins for all government officials and staff available on request. Very similar to the green ribbon but with small alterations showing that it is Saskatchewan, that you can wear, also available to the public on request. Promotions with the driver's licence renewals with posters in the driver's licence issuing offices.

As previous presentations have suggested, are looking for a blanket mandatory — that you're automatically in — donor program in the province where you have to apply to opt out.

Maybe look at an idea, seeing that a driver's licence is not a right; it's a privilege. Therefore to obtain a driver's licence residents must register as an organ tissue donor. Get the government onside, SGI, maybe even offer a discount on the driver's licence. As you've already been informed, in some European and South American countries, organ donation is mandatory.

Continuing to supply more information to the public — display posters, promotional brochures in doctors' offices, medical clinics, ophthalmologists, opticians, and any other medical fields, and in drug stores. Employers with large volume employees: some of the provincial unions, the mining companies, manufacturing companies, municipal and provincial government employees, others. Encourage a challenge to see who can sign up the most employees. Offer nice plaques and recognition.

In waiting rooms in hospitals, also put up some of these organ donation posters. I've spent a lot of time going in and out of hospitals and no one, when you check in or register, has ever asked me if I'm an organ donor. They've asked me if I wear my medical alert bracelet but nobody has ever asked. Yet most of the time there is the little card thing with the stickers and sometimes they're there, and sometimes the stickers are even pulled off.

In high schools, both public and Catholic systems and I believe also the Saskatoon school board has indicated they're looking at some sort of awareness program in their schools. But look at Sask Polytechnic, universities of Regina, Saskatoon, First Nations, and business colleges for the opportunity to promote organ transplants and tissue transplants. The BC group was kind enough to send me what they have on their website for schools. They have a teachers' guide and a one-hour video called *65_RedRoses*. And what it is, is it's about a BC girl who's waiting for a heart transplant. So again they are more than happy to share that with us, so why invent the wheel? Just see if you can get the schools on board. And I'll leave all this for you so that you can view it at your leisure later.

At the transplant hospitals, instead of working from multiple locations here in Saskatoon, they use St. Paul's and RUH [Royal University Hospital]. Maybe move to a permanent location where you can have everybody in one spot. And again just an idea, into City Hospital that seems to have a lot of empty wards, making a Saskatchewan transplant centre of excellence. I believe that would show commitment to the program, attract more professionals to the province, and expand our capabilities. By expanding the capabilities, there's less reliance on other provinces' assistance, cutting costs.

Open up or train existing people for the pre-op and rehabilitation part for transplant people, for physiotherapy. Right now there's only two available sites in Canada, one in Edmonton and one in Toronto. So like myself, I had to stay in Edmonton after my transplant for three months. That's a huge cost to the health care system here.

The ones that are waiting for lung transplants have to go seven weeks to Edmonton for their physiotherapy to get them in shape for the transplant, and then not even know if they're going to get that transplant. Again it would be much more cost-effective if you could do that at home here in our province. Could you maybe piggyback off the program for heart patients currently run at the Field House? I don't know. But I believe in one of the Saskatoon City Hospital promotional ads that they're running right now, they show their physiotherapy department in helping with someone that had a heart attack and is on rehabilitation. Can we build on that?

Another idea: let's recognize people that have passed away that have been donors. You've heard of the Highway of Heroes. How about the Saskatchewan wall of heroes? In our transplant hospital have a wall with plaques showing the names of the organ and tissue donors that have passed away and, if okayed by their family, the family also receives a plaque with their name and "Saskatchewan hero" on it. This wall would have, in the hospital, would have their name with "hero" behind it. I've spoken to, again, some of my students that I have taught and that are now in working with different corporations, and again to find a sponsor for this would be very, very easy and cost the province nothing.

Also to look at cost savings to be achieved, looking at expanding lung transplants in Saskatoon is the next step. I think later today you're speaking to a Dr. Fenton, and I have a funny feeling he may be pressing that thought as well.

So here's my rough idea for your wall of heroes. A couple of people that I've talked to are with mining companies. You take a big rock. You inscribe it as such, and put it in a prominent place in the hospital, similar to some of their examples for donors that they have now.

To gain more awareness, online information through Sask Health plus a donor registry for the province. Or can we set up and develop with other provinces in western Canada? When I spoke with BC and Alberta, they're very eager if this information could be shared.

When I went for my pre-transplant stay in Edmonton, we don't even share our health information with the province if you've been referred out of province. When I was going through all the tests and everything, they couldn't tap into the Saskatchewan system to see if I needed extra X-rays, CAT [computerized axial tomography] scans. Even though I had one in Saskatchewan a week before, they couldn't access that information. So they had to do them all over again and the province got the bill. So sharing of information is very important.

[10:15]

Funding for research. There's a need for a warm organ transplant machine for here in Saskatoon. In your handouts, you have the proposal from Dr. Luo with the transplant group here in Saskatoon of Dr. Moser, Luo, and Beck. Even if the province can't afford right now to give them additional funding for research, maybe send letters of recommendation. This is a federal request. Have the Health minister maybe send along a little bit of extra recommendations for what they want to do.

For when post-transplant patients come home, we also have home care nursing that has to come out, check your scars and everything else. They need better communication with the doctors. Right now, they fax the information to the doctors. It would be nice to equip the nurses with iPad minis, that type of thing, so that they could email the doctors, attach pictures. That way, they could also save time, money, get more patients seen in the day instead of having to go back to their office, write up the faxes, and send the faxes to the doctors.

Yes, we've all seen on the news where this whole lean thing was a bit of a boondoggle. But I worked for a Japanese company. Lean works, except it should be called the proper name of continuous improvement. The systems do work, but it needs to come from the bottom up to have changes in the bottlenecks, the wasted time and money.

From the time I spent in the hospitals they could very well use things like vending machines, vendor-managed inventory. Using wireless information gathering for vital signs — US [United States] hospitals use them. When you get time to look at some of those YouTube videos that I supplied, you'll see where they come in. They bar scan your little wristband. All your information when they take your temperature, pulse, and everything else automatically goes to the mainframe computer and it's recorded. And the nurses don't have to spend all that time waiting, writing things down, and taking it back to the nurses' station.

Also for check-ins, go look at a style like it's done in the airports for self check-in. You're given a code. It registers you, where your little armband they give you, it's printed out no different than your baggage tag and away you go. Again it saves time, money. The people that are doing the registration can spend more time with people that need it. The people that you don't need can now be put on the front lines helping people get in and out of that hospital faster.

Canadian Blood Services, I think you're speaking with them later today as well. Could they play a greater role? I know they do one right now with kidney transplant and matching. Because they also have a list of people that are donators and believe in the cause of donating, can the data systems be shared and work together?

Setting up a department with Saskatchewan Health and attach a transplant office purely to increase set-up. If you notice from the news release that BC had sent out, they have a whole separate department. It's called an agency, so they're not attached directly to the health region. They're a separate entity. Is that maybe one way of looking at it, sort of breaking them off? Yes, you would probably have to hire a few more people, and people is cost. You'd probably need a coordinator, two registration people with follow-up, and a couple of people on the ground in north and south of the province to implement different programs and get your numbers up.

Again, attached with your handout are a number of YouTube videos on transplant. I believe three are from Great Britain. One's from the US, and then there's a commercial. They're all about an hour in length, so no time to look at them today. Some examples of posters that could be used in the hospital waiting rooms and the little main office areas because you need to read something while you're sitting there waiting for the doctor to come to see you. So there's a few. There's one that's pretty striking and drives the point across, one that you can't really read but it says a gift of life, one using the term hero again, and one reminding people that they are six times more likely to need a transplant than be a donor.

So the information again, what BC sent was all with their approval. Again they were more than happy to share information which I will leave with Mr. Chairman. They must be doing something right because when you read their news release, from June 2015 to June 2016 they increased their registration by 50,000 people. I don't think we have 50,000 people even registered. So the program they're using is very good. Again I included in the handouts their website and all the information that goes with it.

Alberta runs an organ tissue and eye donation under their Alberta Health Services. The information that you got was copied with their permission. In fact when I went for my one-year checkup, they actually brought me back to their offices when they heard that I was coming and speaking to you and provided their information, and would be more than happy to speak with anybody on the committee.

You also have the Saskatchewan Transplant information. Again they were established in 1989 for donation and transplant residents of Saskatchewan. And you also have a copy of the research funding that Dr. Luo is looking at from the federal government. He's got all kinds of nice pictures there of pig kidneys and other things that he's been working on.

So again, organ transplant is important. It saves lives and it can save a lot of costs in our health care system. So I'd like to publicly thank BC Transplant, Alberta Transplant, coordinators at the University of Alberta Hospital for the information that's been provided, and others including my sister Rhonda that helped put all this together in a readable fashion, and friends and family that have joined me today here. Thank you very much.

The Chair: — Well thank you very much, Mr. Hofmann. I know some of the committee members have questions already. So we have Ms. Carr up.

Ms. Carr: — Well thank you very much for your presentation. I can see you definitely did your homework, and you have lots of fantastic ideas that can help us with an organ donor program. And I see you also have some great cost-saving ideas in there also.

So you briefly touched on in your presentation the fact that some countries have mandatory organ donation or opt-out programs, right? So I'm curious, if Saskatchewan did something like that with presumed consent where you would have to opt out of a program — you didn't really touch on it a lot, but you did talk about it a bit — how would you feel about that or how would you see that working?

Mr. Hofmann: — I think once you have enough information to the general public and they know more, people I've talked to — and again, younger people — seem a lot more receptive. Some of my smaller friends think that it's cool that you can, you know, some of your parts might live to 100 or more. Also one comment was, it's like recycling, and they're growing up in their lives now where recycling is very important.

It's usually the older generations, and I'm in that category, that have a tough time understanding that. I've had people tell me, you know, you can't do that because the doctors, if they know you're an organ donor, are going to let you die. Well quite the opposite. They do actually even more work to keep you alive to keep those organs going once you're brain dead. So that kind of information has to be shared with the public.

Also that to harvest the organs it destroys the body; and you know, that's not right. So my comeback is, so you'd sooner throw them in the ground and have the worms crawl in and out of them, versus donating their organs, or throw them into a cremation like they're burning in the bowels of hell?

So I think if you can explain this to people, I don't think you're going to get a lot of . . . Plus, you're dead; you don't need those organs any more.

Ms. Carr: — Thank you.

The Chair: — Ms. Rancourt.

Ms. Rancourt: — Well I want to thank you for your presentation, and you have a lot of good examples of some ways that we could do good promotion within our province. But I guess my question kind of relates to the warm liver machine that you were talking about. Because I heard and I want to learn a little bit more about the issues with Saskatchewan is because of we're such a large province. So to get organs from one location to another is also an issue. So can you tell me a little bit more about where your liver came from and about this warm liver machine?

Mr. Hofmann: — When I signed on to the program with Dr. Shapiro, when my liver became available, I believe . . . You don't know whose liver you've gotten until the family acknowledges the fact, and that can take a couple of years.

I know mine came from an automobile accident somewhere in the northern Alberta half. The body was brought to the University of Alberta Hospital, I believe by their STARS [Shock Trauma Air Rescue Society] system. The liver, instead of being put on ice after it was crossmatched and everything, went into this machine. It's about the size of a shopping cart, for a liver, and it processes blood and the bile and everything through it just like it's in your body. It was manufactured and came out of Great Britain. And I know it's, again like everything else, it's quite pricey. But in that instance it keeps the liver alive, I think three or four times longer. And as I said, that way I drove to Edmonton.

So if possible it would be nice to see . . . because of the number of people on the wait-list just here in this province for kidneys — and I think on the transplant site it shows there's approximately 90 — it takes them 2.8 years before a donor is available. Probably a lot of that has to do with, as you said, with the vast geographical . . . By the time they get them, they're not available.

So that means just if you take the 90 that are there — and in the website it says in that 2.8 years they will have 437 times of dialysis, which comes to 39,330 just for the people on the current registered wait-list — I don't even want to know or fathom what cost that is to our health system. So if you could keep the kidneys longer and get the people in and get the transplant rates up, you could probably knock a third or more off that list. So is it worth funding a machine? Yes.

Ms. Rancourt: — Thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you, Mr. Hofmann for your presentation today, it's very appreciated. I want to just comment, your points around not being able to register online or using technology is very appreciated. I think that there's some very sort of simple, straightforward things that could maybe happen.

But I'm curious about your experiences. And congratulations on being well, and I'm glad to hear that you're doing as well as you are. Just that that experience, I think many people in Saskatchewan, if you've never experienced it, don't know about the process. So for a liver transplant it's a week pre-op in Edmonton. Is that right?

Mr. Hofmann: — Yes.

Ms. Chartier: — Okay. I know lung is a six-week pre-op.

Mr. Hofmann: — Yes.

Ms. Chartier: — So can you tell us a little bit about what that waiting period . . . You said there might be a couple of dry runs and what does that look like?

Mr. Hofmann: — Yes. Once you've made their list that they will accept you on the transplant list, you're scored. So for cancer, you get an automatic 20 points. After that you get one point for every month you stay alive. Once you get to 30, 35 you're usually near the top of the list, if you're still alive. And that's when, when a liver does come up and available, they pick the best candidate for that.

So what I was told is, they may have a liver. I might be the best candidate. But in the tests . . . They phone you and get you on your way right away to Edmonton, but by the time you get there, they find something else wrong. The liver might not be the perfect match they want, might not be the right size, or may contain cancer itself.

[10:30]

Actually when I flew home from my one-year check-up, there was a fellow who was on the plane who was being sent back home because he had been called for a partial liver transplant, but when the donor, who was a live donor, was checked out and they got the liver out, they found out this person had cancer, which is a horrible way to find out. In fact that's what happens with a lot of live donors, is they're rejected because they find medical conditions that the donor did not know they have.

Ms. Chartier: — And just out of curiosity, you said in your week of assessment, the pre-op period, of the 21 of you who were there for the pre-op, only two of you were deemed potential candidates.

Mr. Hofmann: — Yes.

Ms. Chartier: — Okay.

Mr. Hofmann: — What they do is before you go to Edmonton you get a great big long list of things you have to have done. One of them, because I'm over 50 there's no record of all the inoculations I had when I was a kid. So you literally have to go and get every inoculation you've ever had done again. There was one day I had eight — two in each leg, two in each arm, and then you have to go back. Everything under the sun — you have to get shingles and everything else redone. If you don't, some people when they were sitting around a table like this said no, we thought when we got here you guys would do it all. They were punted immediately. The doctors don't have the time. There isn't the inventory for everyone, so they're very choosy on who they pick.

That week you have to see a psychiatrist, psychologist. The very first morning was 21 vials of blood that they took. So then you walk around all day with a little urine container. You have CAT scans, PET [positron emission tomography] scans. You have to go on for bone scans. It's a very long and involved process because they want to make sure that candidates that they put on that list have a good chance of surviving because also the costs involved afterwards, of which the Saskatchewan government picks up, is all the drug costs.

And while you're there, they're balancing your anti-rejection meds. Some of these meds are $3,000-a-month-plus, and you're taking two or three of them at the time. So it's a very expensive process. And again if you could be at home here in Saskatoon doing that, you're not paying some out-of-province hospital that kind of money. The sad thing is you might get a month's supply and then a week later the doctors change the medication and you're on a different one that costs a couple of thousand. So there's some huge costs that can maybe be worked at better at home.

Ms. Chartier: — Thank you very much.

The Chair: — We're going to have one more question from Mr. Docherty.

Mr. Docherty: — Great. Thanks, Mr. Chair and Mr. Hofmann, thanks for your presentation. I was particularly interested in . . . I mean obviously this is an issue of education and awareness, primarily. I mean there's other pieces to it but that's primarily the hurdle that we're up against.

I'm interested in . . . You talked about DNR, do not resuscitate, and you also said that a family can veto. I'm interested in what exactly that would look like. If it was my wishes as an organ donor, which I would be, how can my family veto my wishes?

Mr. Hofmann: — That's a very good question. I don't know. It's a law in Saskatchewan and only in Saskatchewan that with organ donation, the family — even though it's your final wish — they can veto that process. And I've yet to find somebody that can explain to me why. So that might be something for the province's legal counsel to find out where it came from and why it's still on the books.

Mr. Docherty: — Yes. Thank you, Mr. Hofmann.

The Chair: — Well thank you, Mr. Hofmann. Before we let you go, we are going to table your document HUS 18-28, Fred Hofmann: Submission regarding organ donation inquiry. I want to thank you for your time today. That was a very thorough, put-together presentation, and we appreciate the information that you passed on. Thank you very much, sir.

We're going to take a very short recess while we get ready for our next presenter. Thank you, sir.

[The committee recessed for a period of time.]

[10:45]

The Chair: — Our next presentation this morning is by the Saskatchewan Transplant Program. I'd like to welcome you to our committee today. Before you begin your presentation, please introduce yourself and anyone that is presenting with you. And if you're speaking on behalf of an organization, please state your position within the organization represented. If you have a written submission, please advise that you'd like to table a submission. And once this occurs, your submission will be available to the public and electronic copies of tabled submissions will be available on the committee's website.

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Our agenda again allows for a 30-minute presentation followed by a 15-minute question-and-answer period. And if you would now please proceed with your presentation.

Presenter: Saskatchewan Transplant Program

Ms. Schimpf: — Thank you. We're here today to represent the Saskatchewan Transplant Program. We have tabled a submission, and thank you for reminding me of that. Myself, I am Erin Schimpf. I'm the provincial program manager for the Saskatchewan Transplant Program. Here with me today is Dr. Gavin Beck. He's a transplant surgeon. He's the co-director for our program. I also have Dr. Rahul Mainra. He is a transplant nephrologist with our program. And then Dr. Mike Moser, a transplant surgeon with our program.

I do have regrets from Dr. Ahmed Shoker. He's one of our transplant nephrologists. He's our other co-director. He was unable to be here today related to faith commitments, but he'd like me to let you all know that he's available after today as you need him to be.

Thank you very much for having us here and for having the public here. We appreciate the opportunity to help educate and to offer some recommendations that we've been working very hard on. I think that it's time for some change to happen in Saskatchewan to increase organ and tissue donor rates. As I mentioned, I did submit a proposal or a report to this committee, and the presentation today is highlights. And we're really looking forward to the opportunity to answer some questions about the work that we do here in Saskatchewan and how we do it. We'd also like to make sure everyone knows that we're more than happy in the future, during your work, to offer any assistance with information or answer any questions as you need us.

So here is where Saskatchewan stands right now. I don't believe this is new information to anybody around this table. I hope it's not. Donor rates in Saskatchewan as of 2015 were below the national, international averages. 2.7 donors per million population in Saskatchewan, living donation, compared to 16 in Canada. Deceased donation rates sat at 8.8 donors per million in Saskatchewan compared to 17 in Canada. And I've thrown out Spain which I'll get to a little bit later in my presentation, but Spain is actually above 36 million I believe now.

Our recommendations are based off a long history of providing excellent care and striving to provide even better care to the residents of Saskatchewan to our donor families, to our recipients, and to our recipient families. We strongly feel that more needs to be done to improve advocacy, education, and leadership through human resource support, donation positions, and front-line staff and physician education. We also believe improvement . . . to improve effectiveness of the Saskatchewan Transplant Program we need to enhance its current governance structure. And we'd also like to recommend increases in funding for organ and tissue donation education awareness primarily for the public.

I'm going to move forward in the presentation, spending some time sharing a little bit about how we came to make these recommendations, and then get a little bit further into the recommendations.

Canadian Blood Services released, approximately 10 years ago, a *Call to Action*. And I understand CBS [Canadian Blood Services] is presenting as well and I'm very grateful for their assistance in that matter. In that call to action CBS brought forward, you can see these recommendations for a national increase in organ and tissue donation. Today what we're going to be doing is focusing more on donor physicians, public awareness, professional education, and resources.

The Human Tissue Gift Act is also an important thing that we spent time looking at when we were coming to our recommendations. This is something that we work with every single day in the work that we do regarding donation. It governs a large part of the work that we do. Other provinces across the country have their own version of *The Human Tissue Gift Act*.

2014, *The Human Tissue Gift Act* was brought before the legislature and it was reviewed. Currently there's work being done on regulations to this Act. That work is not done currently, but some of the important things you can see here listed: required referral, or mandatory referral it's also referred to; purchase of corneas; and improved communication. Improved communication is communication between Sask Transplant and the other health regions and departments in the health regions. But most important in these three topics, by our view, is mandatory referral.

A mandatory referral is just what it sounds like. It would be where all deaths and imminent deaths must be reported to the Saskatchewan Transplant Program. Doing this allows us to have a better connection, a better knowledge of who could actually be a potential donor everywhere in Saskatchewan. CBS did mention this as one of their recommendations.

In Saskatchewan currently, the Saskatoon Health Region is the only health region that has policies that support mandatory referral. We do see this as an opportunity to improve donation across the health regions. That being said, unfortunately the Saskatchewan Transplant Program does not currently have the ability to retrieve cornea tissue or solid organs outside of Saskatoon or Regina. All potential donors are transferred at the program's expense to Saskatoon or Regina depending on what the donation is.

We also took some time to look at the other Canadian organ organizations across the country, or ODOs [organ donation organization], they're often called. It's important to work with our colleagues, and I'm happy to say that we work very collegially with the other programs across the country. ODOs are responsible for procuring organs from both living and deceased donors. The separation of transplant programs and donation organizations protects against actual and perceived conflicts of interest. Provinces with these types of organizations are as you can see.

Now Saskatchewan, our program — STP, the Saskatchewan Transplant Program — we are responsible for donation and transplantation in this province. And that does sometimes, because there is no separation between program leadership or governance, it does cause some challenges for us at time, in specifically regarding the perceived conflict of interest. This can develop trust issues with the public because we're representing both sides of the equation.

Our focus of resources, we have to always choose what we're focusing on at that moment in time, and that as well is for advocacy. What are we advocating for at that point in time? Organ donation and transplantation go hand in hand. I like to say they're like the circle of life, but sometimes you do need to focus on one to make it shine more.

Donation physicians perhaps is the most important thing that we'll talk about here today with you. Donation physicians are specially trained critical-care physicians who champion donation and assist with, as you can see, the following which I will speak a little bit more about.

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.

That being said, in particular, donation physicians have been helpful with DCD [donation after cardiocirculatory death] programs. DCD, I could spend many, many hours discussing DCD — its significance, what it is, how important it is to increasing organ donation in this country and in the world. And I will try to pack it all tightly for you, but please, if you have more questions afterwards, make sure to ask us.

DCD, or donation after cardiocirculatory death, is an option for organ donation for patients with severe brain injuries once a decision to remove life-sustaining treatments has been made. This type of donation, where donation occurs at cardiopulmonary death, use to be the norm. That is how donations started in this country. With changes in medicine, we were moved away from deceased donation from DCD donors and we moved towards donation after brain death. This became the norm and DCD was not talked about any more.

With recent, relatively speaking, recent improvements in safety laws including seatbelt laws, helmet laws, as well as improvements or changes in medicine, deceased donation from brain-dead donors has plateaued across the country and in Saskatchewan as brain death has become less frequent. With that being said, it was with a development of donor physician programs across the country that these group of physicians were able to look at DCD again, make some changes, and bring it forward as an option to help support these people who wish to be organ and tissue donors and fulfill their wishes, which they were not able to do because they would never progress to brain death.

DCD is responsible for the increase in deceased donation we see as brain death plateaued, as I said. It is strictly because of DCD. And DCD programs have become increasingly present in Canada because of donor physicians.

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.

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.

Donation culture. This is also a very important thing that we need to talk about. In countries where focus and resource is placed on building a culture both in health care and in the public, a culture that supports organ and tissue donation, there have been increases in donation rate.

My best example of that is Spain, which I alluded to before earlier, with their very high donor rate. 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. And that is straight from the leader of Spain's ODO. They did have consent, presumed consent for some time, and he has been heard to say that it made no difference at all. Presumed consent creates fear and mistrust in the public. What needs to happen is education and advocacy so people just expect donation to be an end-of-life care option that is brought forward to them, a place where of course we would donate. It's a non-issue, that culture where everyone accepts it as an expectation or right in a province or country.

Saskatchewan Transplant Program. This is us. This is as to the end of 2015. You'll see that there are over 1,000 people that we are involved in the care of there, in various different aspects including transplant and donation, all the way from solid organ to cornea and tissue donation.

[11:00]

You've seen before, in the presenter before me, that Saskatchewan Transplant was started in 1989. We were doing kidney transplants prior to that. Saskatchewan was actually a pioneer in kidney transplantation. Even though we've been around in one form or the other for some time, we continue to face challenges in making improvements, specifically here, to donor rates. Historically the emphasis at Sask Transplant has been placed on transplantation, and this has been a challenge to help us realize increased donations across the province.

One of the challenges we face at Sask Transplant is a lack of a clear governance structure. You can see that we have a division of governance and authority between the Saskatoon office and the Regina office. In Saskatoon we're located at St. Paul's Hospital second floor, and in Regina we're at the Kidney Health Centre on north Albert. That being said, the division between the two offices creates a very complex and sometimes awkward governance structure.

Saskatoon is responsible for governance policy procedure and how we do our work, but the office in Regina is also governed by RQHR [Regina Qu'Appelle Health Region], which leads a complex element into getting work done, and policy and procedure introduced into another health region which we technically do have no authority over. So that being said, you can imagine that confusion and complexity increases even more to reach out to the other health regions in our province.

And then we have, we're compounded by the size and geography of Saskatchewan, which you've talked a little about already, I understand. Again, our governance structure, there's a sense of lack of authority — not a sense, there is a lack of authority — for Saskatchewan Transplant across the province.

We lack an organ donation organization and donor physicians. This creates challenges and barriers to providing service to the residents of Saskatchewan. It can develop, as I've spoken about before, a sense — perceived or actual — of conflict of interest that our same physicians are caring for donors and recipients. And because we lack those donor physicians, moving programs forward to support things like DCD, mandatory referral, education, advocacy, awareness is very difficult when we don't have that champion guiding us on the donation end of things. Currently STP [Saskatchewan Transplant Program] does not have the resources to effectively focus on both transplantation and donation, as I've spoken about before.

This is a very big slide. Saskatchewan Transplant, we've got a lack of human resources to care for donors and recipients. This is a list of what we do at Sask Transplant. We assess for transplants, primarily kidney transplants, but we do provide some assistance and assessment for heart, lung, liver transplantation. We manage the kidney wait-list for Saskatchewan. We provide ongoing care for recipients of solid organ transplants, primarily for kidney, but as you can see from an earlier slide with our patient numbers, we do work with primarily the Edmonton program to provide care for liver, heart, lung patients in this province.

Assessment for living kidney donor and living bone donation; retrieval and transplantation of kidneys; retrieval of cornea, bone, tendon, and heart valve from diseased donors. We work with Edmonton's Comprehensive Tissue Centre to do that. Education and advocacy for organ and tissue donation across the province. Quality and improvements to meet accreditation standards with Health Canada. In transplant, we need to be accredited with Health Canada, and we also do accreditation within our hospitals. And then we're responsible for care of individuals with pulmonary hypertension. So that's a long list.

I can tell you we have 17 staff in Saskatoon and five staff members in Regina. As I said before, the divide is Saskatoon is responsible for policy and procedure. We also manage the wait-list out of Saskatoon. And our tissue office is, that is where we do retrieval of bone, tendon, ligament, and heart valves. And we've got social workers, pharmacists, admin, and of course RNs [Registered Nurse].

The staff are responsible for these areas that you've seen listed, but they are also the RNs responsible for providing 24-7, on-call coverage for the province. Unfortunately when a donor situation does arise, of course immediate attention goes to the donor situation, and that is that staff person's focus. This takes them away from the other patients that they are responsible to care for. So essentially one person is getting less because another needs more.

Both transplantation and donation patients deserve the best possible care. Unfortunately current resources create a situation where one takes away from the other. To give an example for that, we have four nurses, four part-time nurses who are responsible for caring for almost 500 kidney recipients in this province. And so all four of them are part time, and when there's a donor situation, at least one of them gets pulled away for a day to perhaps up to two days to provide care in coordinating a donation situation.

Based on the challenges, because these challenges are not brand new to this province, in 2014 the Saskatchewan chronic kidney disease program and their steering committee communicated strategies to improve donation, and these will come as no surprise. They advocated for DCD, donation physicians, an update to *The Human Tissue Gift Act* — which I'm happy to say is under review — mandatory referral, and an increased focus on donation. These recommendations, and I've mentioned this before, have proved useful in increasing donor rates across the country and are all supported by research of Canadian Blood Services, Canadian Institute for Health Information, and our CORR registry which is Canadian Organ Replacement Register.

I wanted to make a few points before I get into the recommendations, which is the next slide. Donation of solid organs, all solid organs, is possible in Saskatchewan. Unfortunately there's a misconception in the public's eye that donation of kidneys is all that is possible in Saskatchewan because that's all we transplant in Saskatchewan. It is a misconception.

In Saskatchewan we work very closely with all other ODOs, organ donation organizations across the country to make sure that if at all possible, all organs find their way to a recipient who needs that organ. A great example of that is, if we have an organ donor who, where it's viable to donate all organs, it is not unusual for Saskatchewan to receive the kidneys but someone to come from BC for lungs, someone to come from Quebec for heart, someone to come from Edmonton for liver and pancreas. And that's our coordinators' work. That's what they do. They spend their time making sure that this person, this family's wish, is respected.

That being said, only 1 to 2 per cent of all deaths will ever occur in such a fashion that supports organ donation. People who can become organ donors must be supported on life support before they become an organ donor. That is also a common misconception in the public. A deceased person can become a tissue donor but not an organ donor. You must be sustained on a ventilator to become an organ donor.

There are many misconceptions about organ and tissue donation, and I think perception is reality. And it's important to spend some time to really get to the heart of what organ and tissue donation programs, what they do. So education is essential.

To respect the wishes of all those who may wish to donate, Saskatchewan Transplant Program believes we can improve organ and tissue donation in Saskatchewan through what you'll be seeing next, the recommendations that we're bringing forward. And this, we sat down of course as a group, as a program, to bring forward these recommendations.

Number one, these will come as no surprise. We need to improve advocacy, education, and leadership through human resource support, donation physicians, and education of front-line staff and physicians.

Human resource support — we've talked about this already — transplant and donation are linked. You can't have one without the other. Currently, care of one group is slowed to provide care for the other. More resources are needed so each group gets the focus it deserves.

(b) Donation physicians. New programs and initiatives are set for failure without this group to act as a champion. We cannot emphasize enough — and this can be seen through DCD and mandatory referral — that donation physicians can make these things happen through education, research, awareness, advocacy, and collaboration.

(c) Education for front-line staff and physicians. This is important in building that culture to accept organ and tissue donation as a norm. Every patient who can become an organ donor, that meets requirements, should be able to donate their organs or tissues as they would like.

Our second recommendation is to improve the effectiveness of the province's existing transplant program through enhancements to its governance structure. This, we appreciate and respect, would be a significant and very complex undertaking. What we recommend is that a coming together of stakeholders across this province, including the public, to discuss how we can most effectively provide the best possible care to our residents.

And our final recommendation is to increase funding for organ and tissue donation education and awareness to develop a culture that supports donation. This can be done through public awareness campaigns and collaboration with our First Nation and Métis communities.

Public awareness campaigns. We have been fortunate to receive directed funding for awareness campaigns, in particular the last few years. You may have seen our Offer Hope campaign that happened about two years ago. And this is funding we received from ministry as well as from some other organizations, specifically the Lions Clubs of Saskatchewan, to put together a six-month awareness campaign. There were posters and we had a presentation out at St. Paul's Hospital.

We did see increase in interest in donation from that campaign. But because it was directed funding, that interest comes and then it dwindles, burns hot and it dies out. What we need to see is ongoing awareness campaigns, ongoing education in the province, so this donation is always on people's minds. It's always easy for them to speak about. This assists in making donation a norm in any community, and that's where we need to be. It's a normal thing for organ and tissue donation.

(b) is a little bit more complex, collaborating with our First Nations and Métis communities. First Nations and Métis communities make up about half of the people in Saskatchewan who have chronic kidney disease, yet only 15 per cent of those people have received a kidney. There's been minimal engagement and collaboration across Canada to work with First Nations and Métis communities to understand these numbers better. This group makes up a very important part of Saskatchewan and understanding where they're at with education and awareness, I think, is important to move forward in offering them the best possible care.

Transplantation is the gold standard, best possible care for chronic kidney disease. Every individual, if eligible, should be offered donation as an end-of-life care option. That's what needs to come out of increasing public awareness.

In conclusion, if emphasis is put on these three recommendations, we do strongly feel that we can realize increased donor rates over the next three to five years. We have the potential in Saskatchewan to do this. Saskatchewan is a giving province. We just have to make sure they have the resources to get there. We can make it happen. Thank you.

The Chair: — Well thank you very much for that presentation. Very detailed. That was very nice. We're going to start with questions. We have Ms. Rancourt up first.

Ms. Rancourt: — Thank you for your presentation. I know for myself I was really excited to hear that you guys were on the list to come because I think you are able to answer a lot of the questions that we have. And when you talk about donor physicians, that's been something that I've been hearing more and more also that is needed. And so I've got a couple questions I'm going to wrap up into one because I got a lot of other ones as well.

So when you talk about donor physicians, what kind of training is required for physicians to have that classification? And is this something that RNs or nurse practitioners could also get training in? And then I guess my other question is, what currently are physicians and health care professionals being trained in with regards to knowing who makes a good donor?

Mr. Mainra: — So I think the bulk of our donor physicians sort of are . . . And if you look at that across the country, it would be either intensive care staff physicians or emergency department staff. Within their training, as they become trained emergency physicians and intensivists, they have a large aspect of that training that's pertaining to organ donation and the care of an organ, a potential organ donor. So we have various intensive care physicians in both Saskatoon and Regina that are fantastic donor advocates for us. And we work hand in hand with them, and we've shared this presentation with some of those champions already.

[11:15]

So technically there wouldn't be a lot of extra training that would be needed for those physicians to take on that role. It would be more sort of protection of their time to allow them to continue that education, to continue that advocacy of other physicians within their departments, within either the ICUs or the emergency departments, and across the province.

So I think it's, you know . . . We have various physicians who are already at that level that could step into that role. It's about protecting that time for them. It's about taking them away from caring for other patients and giving them the time that they can spend on potential organ donors and improving the advocacy of organ donation across the province and within their hospitals.

The Chair: — One more . . . [inaudible].

Ms. Rancourt: — Okay. So I know there's a lot of trained individuals in Saskatoon and Regina with regards to this. But I come from Prince Albert area and the people I have been talking to, a lot of people feel that signing up to be an organ donor, there is no point in doing it because if you live outside of Saskatoon and Regina the likelihood of donation is very low. And so I know there are some medical professionals in other health regions or other health districts that would like to have this training.

And I'm glad you guys brought up the ethical component to it because family physicians don't feel that it's something that . . . It's kind of a conflict for them to be able to approach their own patients with regards to organ donation, so it'd be good to have a few people in all the different health regions that are able to do that. And I know it takes away from their other patients that they're serving but I think it's a real necessity, especially if we're going to increase the donor population.

And so again I guess the specifics I'm trying to get is, how long would a program take for a person to be able to call themself a donor physician? And what kind of education do they need outside of what they regularly get to be able to label themselves as such?

Mr. Mainra: — So if you look at Australia and what they've done is they've put together an actual course where they have, and as you mentioned, nurses, other health care providers that attend this course that goes through all the nuts and bolts of caring for organ donors, speaking to family, and proceeding with the donation process.

And I think we have . . . So in our main two major cities, Saskatoon and Regina, there are definitely intensives and critical care staff that could basically run that course because they do that all the time within their portfolio. And the important part is having those donor champions across the province. So wherever there is an intensive care unit in North Battleford, Prince Albert, Moose Jaw, and other places, we have a donor champion in that area that would be trained by our local donor physicians, by the main donor physicians in Saskatoon and Regina.

And I would say that, you know, it would be, I would imagine . . . We would have to collaborate with our intensivists, but I would imagine it would be a weekend course, really to give them the education, to give them the know-abouts to be able to approach family and to approach the care of that potential organ donor and that patient. But it's about having those champions locally obviously within the main centres, but also across the province because, you know, a physician in Saskatoon can't be at all places at all times.

And Ontario has done a fantastic job of that. They've initiated donor champions in each of the smaller regions across their vast province and they've seen a huge increase in their organ donor rates as a result of that.

Ms. Schimpf: — I didn't get an opportunity in the presentation to note, in the PowerPoint, but in the submitted presentation I do make note that we at Sask Transplant have submitted a proposal to the ministry to begin development of an organ . . . pardon me, a donation physician program.

The Chair: — Mr. Docherty.

Mr. Docherty: — Thank you, Mr. Chair. And again, thanks for the presentation. I've got about three different comments and whoever would like to take a shot at all of them. But I'm interested in some of the reasons why an individual or a family would opt out, that they've given you, in terms of donation. I mean, you're right at the front lines.

So what are people saying, number one, as an individual of why they wouldn't want to be an organ donor? And why have families circumvented, maybe, their needs? Secondary, you talked about the conflict, and Ms. Rancourt also discussed the conflict, but I'm interested in how that conflict might be resolved in terms of . . . and also in light of the recent move towards assisted dying. And you've talked about, you know, life support as one of the pieces. Is assisted dying going to maybe lead to more donations? And I'm not sure whether or not that's even possible, but those three I'm interested in.

Ms. Schimpf: — I can speak a little bit to some of the reasons the staff have faced for people to choose not to donate. Surprisingly lower on the list is reasons of faith. Quite frankly, all the major religions do support organ and tissue donation, but we do get some and that's okay. If their faith leads them to not donate, that needs to be deeply respected.

One of the main reasons the coordinators will hear is that they don't know what their family member wanted and they just, they can't make that decision in the moment. They just can't do it. It's the furthest thing from their mind. It is, quite frankly, the worst day of their life, that day. And that would be why we spent a large amount of our time in presentation saying, the most important thing you can do is talk to your family and friends, let them know what your wish is. Because if that moment occurs, take that burden away from your friends and family.

I'll let one of the physicians, maybe Dr. Beck . . . the conflict of interest?

Mr. Beck: — So in Canada, with other provinces, we do have well-established ODOs that are separated from the transplant side of the transplantation community. As far as the perceived conflict, currently, right now all of our staff working on the front line, working with the intensivist, working with the social workers at the bedside of that dying patient, they do have other responsibilities and they do day-to-day work with the recipients of our province. And so if we move towards having a program where there is separation of donation and the transplantation side, hopefully that will remove some of that perceived bias.

As far as actual bias, we work every day to the best of our ability for both the recipient and for the donors to respect all wishes. And we do our very best to avoid any conflict but of course it's hard to remove the perception.

Mr. Mainra: — Assisted dying is an interesting topic that you bring up. And actually, we're having our Canadian transplant meeting next month and one of the main plenary sessions is about assisted dying and whether or not donation can fit within that frame. So it's difficult to know at this stage. There are countries in Europe who have done such things and have discussed having donation after assisted death, but I think in Canada at least it's very preliminary, and how that plays out will be an interesting process.

The Chair: — Ms. Lambert.

Ms. Lambert: — Thank you. Thank you for your presentation, Erin . . . [inaudible] . . . I'm also in need of education, so one of my questions is about living donors and what exactly that entails. I know there's kidney donation — you can live with just one — but I don't know much beyond that. Also you've talked a lot about donation physicians and explained to us some of the reasons, some of the challenges for donation physicians. But I also wonder if it's your opinion that because we have such a low rate of people that are willing to get involved in organ donation, if that's part of the reason why donation physicians seem to be a challenge for you. So just a couple of areas.

Ms. Schimpf: — Living donation in Saskatchewan is living kidney donation. Our program does facilitate that for directed living donations, so if I had a loved one or someone I knew who needed a kidney, I would come to our program. — you must self-refer to the transplant program — and we would help that person make that donation.

We also have people who come forward that do not have someone they know who needs a kidney. They just feel compelled to donate, and that's called altruistic donation. And we are quite fortunate to get to work with CBS and the other programs across the country to facilitate living kidney donation through the kidney paired donation program, and that links people and programs across the country to enable people who would never get a living donor kidney. They make that possible.

In Saskatchewan we also have living bone donation. People who are going to have total hip replacement surgery, if they consent they can have the bone that is removed — the femoral head — they can have that donated. And we use it for other surgeries such as spinal surgery. People can work through other provinces to living-donate livers as well, and I think we're doing living lung but very rarely, correct? Of course, not in Saskatchewan, but in some of the other programs that do lung transplantation.

Does someone else want to field the donation physician question?

Mr. Moser: — I think one of my favourite words in transplantation is culture. And five out of the six physicians on the transplant team in Saskatchewan here did their training in London, Ontario which is a great example of a place with great culture. In fact apparently . . . This is their statistic. They say they've got one of the highest organ donor rates of any city in North America. And it is culture; it's getting out there and talking to people, educating staff, educating people around.

But a big part of that is the donor physicians. And a lot of what Erin presented today keeps coming back to the donor physician part — whether it's the culture; whether it's the separation of the organ procurement organization and the transplant team, the team that puts the organs in; the education. So I think that's really a key component.

Now when we bring this up, a lot of times the objection is that it costs, it costs to have physicians on 365 days a year, 24 hours a day. 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.

It's not hard to fathom that mathematics because, when you think about it, the cost of dialysis — and this is from the Kidney Foundation data of a few years ago — $250,000 per four years of dialysis per person who's on dialysis, who's on the wait-list. So factoring that in, and that's only one of many factors, it's something that's highly cost effective. And so to me, everything comes back to culture and to the donor physicians.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you very much for your presentation here today. And I would like to actually focus in a little bit on the donor physicians. I know I've had a conversation with your program a year and a half ago about donor physicians, and I had a hard time wrapping my head around. So for my colleagues here, what I understood donor physicians . . . So you carve out a little piece of your time as an intensivist in your regular workday or the cycle of your workweek, whatever it might be. But it's about relationship building.

What I recall you talking about is missed opportunity; so if there was a donation that could have happened, you review those to see what could happened differently. You work with your colleagues to help them understand who makes good donors, because I think what I heard you say at one point in our conversation a year and a half ago, was that many people . . . If you are an elderly person, people think you can't be a donor.

So I think I do have a couple of specific questions around numbers and things like that, but I know I had a hard time wrapping my head around what a donor physician does. So they would be working with their colleagues and helping them understand how to do this better, but would they also be working with families as well? So a donor physician in Saskatoon, is he or she simply working with his colleagues or with families as well?

[11:30]

Ms. Schimpf: — The answer is yes. It's a very varied role, and each province does it a little bit differently. So in the proposal that we put forward to the Ministry of Health is we asked to start with two — one in Saskatoon, one in Regina — and come together and let's figure out what would work best in Saskatchewan because ultimately we would like to see donor physicians in all the ICUs in Saskatchewan. So you had, as Dr. Mainra referred to before, that champion everywhere across the province for organ and tissue donation.

Their job does include, as you've said, the education and awareness with their colleagues, not just physicians but then other nursing and allied staff as well as family there, and even broader, the research, the looking into missed opportunities, death audits, and so on. It's a very varied role, and one that really needs to be defined for what works best in Saskatchewan and our population and our geography challenge.

Ms. Chartier: — Just on the specifics then, I think I heard you say two things here then. You're looking for . . . did you say a donor physician training program, or just a donor physician program?

Ms. Schimpf: — A donor physician program.

Ms. Chartier: — Program. Okay, that's . . . Sorry, I misheard you there. So you're just asking for two. I know a year and a half ago you were hoping for two in Saskatoon and two in Regina, in previous conversations. You've scaled that back a little bit?

Ms. Schimpf: — We scaled it back because there are so many different types of programs across the country and internationally. We need to find one that fits for Saskatchewan.

Saskatchewan's spread all over this huge, beautiful province, whereas some of our neighbours — let's take Manitoba, for instance — everything is right down at the bottom and that's where their focus is for locale of their donor physicians. We have ICUs, unlike them, widely — and big ICUs — spread across the province. We need to facilitate that better.

So by only asking for two, it's clear in the request or the proposal that that is a stepping stone to coming forward with a bigger proposal that will facilitate donation across the province.

Ms. Chartier: — Can you help us understand a little bit about what the proposal looks like? Obviously we haven't seen your proposal to the ministry, so can you tell us a little bit about how that would roll out?

Ms. Schimpf: — The proposal looks much like our report to this committee for background information in the importance of donor physicians. And then it is essentially as I said, to hire two part-time staff members, to bring them together to build a program but then to also immediately start work on programs like DCD and assist with mandatory referral which will be coming soon, I understand, through regulation work from *The Human Tissue Gift Act*.

It's very simple, the proposal we put forward because we know that the ultimate program will be much more complex, and we can't do it ourselves at Sask Transplant. The donors and donor families, they're not our patients. They're patients of the intensivists in the ICU, and we need them to make these decisions and to build this program to provide the best possible care for these people.

Ms. Chartier: — Are you asking in the proposal for donor physicians or two staff people to set up the program, then?

Ms. Schimpf: — Two donor physicians, part-time donor physicians.

Ms. Chartier: — Two part-time donor physicians. Okay. Thank you very much for that.

The Chair: — Ms. Carr's going to wrap it up with the questions.

Ms. Carr: — Great. Thank you very much for your presentation. You talked about *The Human Tissue Gift Act* and how it's being reviewed right now. So I don't know if you heard earlier, but apparently in Saskatchewan a family can veto a donation if they don't want it to go forward. So is that something that we can deal with in that Act, or is that not a question for you?

Ms. Schimpf: — No, I'm kind of monopolizing the mike, but *The Human Tissue Gift Act*, vetoing consent, it's a misconception unfortunately in the public that this is just a Saskatchewan concern. Across the country and across the world, families can choose not to consent to donation even if they are aware that their loved one wanted to donate, and that is regardless if a country or province has an online registry or a paper registry of some sort. That is the practice across the world, even in countries like Spain, with presumed consent, they would always still go to families and talk to them about consent. I believe it's a country in Asia, that they're one of the very, very few where it's black-and-white presumed consent. But almost all other programs, they talk to the family.

Ms. Carr: — So can we deal with this in the human tissue Act or no?

Ms. Schimpf: — I think *The Human Tissue Gift Act* lays out that a person can consent. It is practice for families to be talked to.

Ms. Carr: — Okay. Thank you.

The Chair: — We're going to allow one more question from Ms. Chartier, and then we're at the end of our time.

Ms. Chartier: — Thank you. With respect to mandatory referral, so you'd said that Saskatoon Health Region is the only region that has policies in place. Are you hoping . . . So obviously *The Human Tissue Gift Act* has been passed and working on regs right now. So will that be dealt with in the regulations then? Or how do we ensure that every health region has a mandatory referral process?

Ms. Schimpf: — Once the regulations are complete and they're rolled out, we're in the beginning process of rolling out a plan where we go to visit all the health regions to discuss mandatory referral and assist them with education, advocacy, what resources do you need to effectively do this. We also start at the basis of a process to get the referrals to Sask Transplant, be it here in Saskatoon or in Regina, to follow up with those potential donors.

The challenge, as I mentioned in the presentation, is that mandatory referral for imminent deaths, which would bring us to our ICUs and our ERs, involves donor physicians because we don't provide care for those patients. That would be a very grave conflict of interest. So we need someone from that donor physician group to come with us to advocate, to collaborate, to make that process as good as it could be so we realize increased donation from the rural facilities.

Ms. Chartier: — Okay. Just one more, sorry. With respect to donor physicians, I know we talked about Ontario. And Dr. Moser, you come from Ontario, did your training there. But are the donor physicians in other provinces as well?

Mr. Moser: — Yes. In fact we're one of the very few provinces that doesn't have donor physicians. And definitely we've seen the impact that it's had in BC. Notably in Ontario, you know, prior to donor physicians compared to after the donor physicians became a part of those programs, the difference was huge.

Ms. Chartier: — Okay. Well thank you for that. Thank you very much for your time.

The Chair: — That opens up one question for me, and it'll be a quick one. Is donor physicians something that's required in regulations or a directive to health regions? Because it's more than just money, how do we roll this out?

Mr. Mainra: — So yes, I mean it's definitely more than money. Money is the first step. It's having also physicians in each centre. And ideally to start off in Saskatoon, Regina, and then in each of these health regions as we move to mandatory referral, they're going to have questions. It'd be great to have champions in each health region that those questions can be filtered through.

And then setting up the basis of a program, yes we ask for two part-time physicians in Saskatoon and Regina, but that very quickly, once we have people across the province that are willing and wanting to do this, will get very big. So it's about having . . . supporting those physicians financially but also from what we can do from the transplant side, but also as a governance on the donation side of things, and providing them with the governance to form a donation organization that would allow them to go into health regions to discuss mandatory referral, to discuss donation, with their team members. Education for the physicians that are here to be able to take that education out to the periphery, to the smaller health regions.

You know, it would very quickly become a very big program with various deliverables, but we need to start somewhere. And I think having, you know, a couple of people in these main centres to come together and put together a fairly structured program where we can then take it, where they can then take it to the rest of the province, would be ideal.

And in addition to the advocacy education, ICU is a very busy place. So those donor physicians would also be sort of given the care of that potential organ donor. So if there is was an organ donor within the intensive care that week, it would be one of the responsibilities of that organ donor to take on the care. Because having an organ donor and caring for that organ donor going through all the tests that are required to be a liver donor, a heart donor, a lung donor is a lot of work. And in a very busy intensive care unit where you have many, many other sick people, intensivists have a hard time with that. And my wife's an intensivist, and I hear that all the time at home where it's very difficult to be able to spend the time with the donor family, with the donor patient, plus be managing all the other very sick, critically ill patients.

So it's taking that responsibility away from the rest of the intensivists which also has other, sort of issues with respect to how they feel about being in conflict of interest. So it's taking that decision, that responsibility away from the other intensivists and having that sole donor physician who is able to talk to family, coordinate with our team when it comes to allocating these organs across the country and moving towards donation.

The Chair: — Well again, thank you very much for your time today. Before you leave, we're going to table HUS 19-28 which is Saskatchewan Transplant Program's submission regarding organ donation inquiry. And again, thank you for taking time out of your very busy schedules to present to us.

We're going to again take a short recess, real short one, so we try and keep on time and be respectful of everyone's time. Thank you very much.

[The committee recessed for a period of time.]

The Chair: — And we're back at it. So before we get started, I want to table HUS 20-28, Sharon Melnyk: Submission regarding organ donation inquiry, dated September 12, 2016. Our next presentation is by the Canadian Blood Services, and I'd like to welcome you to the committee today.

Again, before beginning your presentations, please introduce yourselves and each one of you that may be presenting, and if you are speaking on behalf of an organization, please state your position within the organization. If you have a written submission, please advise that you'd like to table a submission. Once this occurs, your submission will be available to the public. Electronic copies of the tabled submissions will be available on the committee's website, and once your presentation is completed, the committee members may have questions for you.

I will direct the questions and recognize each member that is to speak. Members are not permitted to engage our witnesses in any debate, and our witnesses are not permitted to ask questions of the committee. Our agenda allows for a 30-minute presentation followed by a 15-minute question-and-answer period. And if you would now please proceed with your presentation.

Presenter: Canadian Blood Services

Ms. Young: — Thank you. I'll begin by saying my name is Kimberly Young. I'm the director of donation and transplantation at Canadian Blood Services. Thank you for the opportunity to present to this committee. It's our true pleasure to be here with you today. We will be submitting both our presentation and a national progress report of data on the system that was released on Friday which we will highlight in our presentation and encourage you as well to table that presentation, that document.

Mr. Nickerson: — My name is Dr. Peter Nickerson. I'm a kidney transplant specialist and medical adviser for donation and transplantation. I'm based in Winnipeg.

Ms. Young: — So within Canadian Blood Services, within the role, I've had many, many years of experience in organ and tissue donation and transplantation, the previous chief executive officer for the Canadian Council for Donation and Transplantation, and many years involved in the system itself in Alberta.

All right. So the objective of our presentation today is to continue building on our perspectives on opportunities for improvement in the system in donation and transplantation. Talking about the 10-year system progress report, as I said, we will introduce highlights. These findings are encouraging, and we want to share some of our perspectives that we've gained through the work of our advisory committees at Canadian Blood Services. We have over a dozen committees that make up representatives of leadership in donation and transplantation across the country. We want to encourage you that there are many improvements we're seeing today, but further to go, and we'll certainly highlight those pieces.

We as an organization provide national programs and services that are intended to work in harmony with the provincial programs and their improvements. We want to highlight as well we have had much exposure and support from our international leaders. So we heard in earlier testimonies about programs having great successes around the world. And we want to assure you that not only do we know those leaders but we work with them on a routine way, and they've contributed to the report that was introduced by the previous presenters, the *Call to Action*, a national strategy that was put out in 2011 as a road map. That road map was informed by those very leaders that have been introduced here today. So we'll try and highlight some of those points throughout our presentation as well.

At Canadian Blood Services, some of you may be wondering why are you involved in organ and tissue donation and transplantation, and to what degree is your involvement? So first of all we are obviously and continue to be very engaged as a biologics manufacturer and a clinical service provider. Blood, plasma, stem cells — those are our areas of work. But since 2008, it's been our role for leadership and coordination in the organ and tissue donation and transplant system in Canada. So what does that mean? We actually offer and provide national services that are supporting the programs here in Saskatchewan. And I'll take you through some of that work right now so you've got a better idea of what it means and what our involvement is.

So first of all, a busy slide, but when you get a chance to put it in front of you and really see it, what this is trying to depict is the network, the many different programs and services that are contributing to the successes and to the services we see in donation and transplantation in Canada. So you see a number of national programs are integral to support what happens in the programs here in Saskatchewan, including the work of Canadian Blood Services, but also we in turn work in harmony with the provincial programs, the transplant and the donor program. We're also encouraged and supported by patient groups, medical associations, professional societies. All of those groups have an important role, and they all contribute to making the system better.

So you'll hear us talk about the network in many places, and it is truly those people in those specific roles that come together to advise and advance processes and policies.

This is how we divide the four areas of focus that we work in. So first I'll start you on the top right corner. We have the responsibility of creating a national strategic plan; what are the most important things we should do as a nation to evolve. The previous presenters introduced that. That plan still stands as one of the best and seminal pieces of advice we can direct your attention to. In the area of donation improvement, the pieces are still there. They're still relevant. They're still timely. We also bring together a network, a community to do the work that we do in developing leading practices, in developing the national listing, in sharing policies. We do that with representatives from this province and others.

We heard in the earlier presentation around the need for governance in the provincial programs. We also are establishing and need to reaffirm the governance and the direction for the national programs and services. Truly what we need to see happen is that we need clarity at the provincial and the national level. We need to harmonize how they work together, how they set priorities, and then as a country we can continue to advise on and report on the progress. So that's something that we're looking and striving for as well in our clinical governance that surrounds the services we provide.

The Canadian Transplant Registry and patient programs and services, I'm going to highlight more of this work. But these are truly the big offerings that we didn't have 10 years ago as a country and are serving you well here in Saskatchewan. National living donation programs, national sharing so that, when your sickest patients need help, you look to your partners across the country and they have policies and processes to share those organs. And in turn you're often supporting someone in another province with one of your donors, as was described earlier. So it's that intricate network of how we share, and we'll talk more about that.

System performance data, the data that we've tabled today. We can't provide improvement in this system if we don't understand the data. For many years prior to now, there was not that consistency or that transparency on the data. That system has changed; there has been much work as a community to get that data together, to get it produced, and to get it out in a timely way. So we're very excited about that. So this committee and others like you can deliberate with real-time data. That's important.

And finally, you can't make changes unless you're doing so in an evidenced way, in scientific communities as those we represent here today. So it's so important that we look at the world best practices and we bring them in an appropriate way to our county.

But making those recommendations is not enough. We've done that at the national level. It's implementing them in the provincial level that is so important. And we heard earlier much discussion about things like the donation specialist approach. There is a national guideline on that, and many different ways we can think about the application.

Again, providing professional education, there is much we've learned — not only as a blood service provider and how you attract and retain donors in that system — that can be leveraged into advancing the public awareness programs in the provinces. Similarly, professional education programs. 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.

[12:00]

So the Canadian Transplant Registry, for a short focus here, what can it do when it's completed? And we're on the home stretch with this service, the last few months. It's a web-based service that helps to track all organ donors and link them with all potential recipients. That's already built and working, and the last phases are advancing it. It'll help us to share organs nationally, provincially, regionally. Organ-specific policies are part of this, and program-specific policies could also be introduced. And again, and most important, it generates all of that data so that we can then really understand the system.

So that's basically what it looks like. It's an integrated network.

You're using it today in Saskatchewan. In a few months it'll be fully complete and we'll be able to do much more with it. This is a quick look at it, so every living donor, every deceased donor, matching that with how you share organs, the ability to share locally as well, that wait-list in real time. The registry itself is what we offer to get all of this sharing done, and then the data collection at the end of the day. We're happy to talk more about this at the end.

So a little bit more about that wait-list that I introduced and the sharing, and I heard some questions to this in previous discussions as well. So the wait-list should be up to date and everyone using the same practices to list people so that there's a fair access in our country, and sharing then by the highest or sickest all the way down to . . . If we can't find an organ match in this country, let's look beyond here and make sure no organ opportunity for transplant goes unused.

So those are the processes that we're working through for organ sharing and the policies that we're building. And remember we're evolving a very informal series of gentleman's agreements into a very structured process for sharing that's very transparent and optimal. Other countries have had this for many, many years, and we're now finally going to deliver this full piece in Canada in a few short months. So we're very excited as a part of the national leadership to work with this province on this work.

Just a couple of things that you would have seen that are already in place and being advanced. So we've talked about it and I've introduced it: the kidney pair donation. If you and your spouse went forward to be . . . one to offer an organ and one to receive, but you found out in testing that that would not be possible, you were not compatible, putting you both into a bigger pool of Canadians that actually want to do that, you can find a potential other match somewhere beyond your doors here. My husband as the donor would donate to someone in British Columbia, and somebody in Nova Scotia turns out to be the best match for me. And so we've made that connection happen through an algorithm that we run through Canadian Blood Services, but this would be lost if we as a country didn't work together, and we do. So those policies are in place and already over 13 per cent of all donations from living donors in Canada are as a result of this registry.

The national wait-list I introduced, again so important that we understand the wait-list and access to that important opportunity of transplant. We've all got to use that in the same way because we share organs based on wait time, so access needs to be built and trust needs to be built through that wait-list.

And finally the highly sensitized patient program — again another collaborative effort. This was patients that were sensitized and very difficult to match, especially in single programs. But when we open those doors, and again we created that bigger pool, magic happens and we're seeing equitable access. More people of this sensitized nature are being transplanted and today over 250 people, which is a massive number . . . Because many of those people died in your own province waiting because they were too sensitized to ever find a match from the few transplant opportunities they had here.

So at the end of the day back to, it takes us working together to see these improvements. And so much of what we heard in the previous presentation, the work that we can do informs and supports and then is implemented in the provincial programs.

I'll now turn it over to Dr. Nickerson to talk you through some of the highlights from the report we released this Friday.

Mr. Nickerson: — Thanks, Kimberly. Mr. Chair, hon. members, I'm going to take you through a lot of the data and then try from that data to take some of the learnings that we're seeing in the country. So this is the 10-year report between 2006 and 2015. It's really the first high-level system report that's been produced in Canada collaboratively by all the network members. So this is not Canadian Blood Services preparing this report. This is a report provided by Canadian Blood Services and all its jurisdictional partners.

The key findings of the report is that in general, Canada's organ donation and transplant rates are on the rise. Since 2006 we've seen the rate of deceased donation go up by 29 per cent, and now we're among the top 20 in the world. The number of transplants has increased by 23 per cent in Canada. And in terms of living donation, three provinces in Canada are close to reaching the national set first-year target of 20 living donors per million.

Now to dive a little deeper into deceased donation, this is the international comparison across the world. And we benchmark ourselves in particular against Australia, the UK [United Kingdom], the US, and Spain. These are all in dark green. Canada last year was at 18.2, on par with Australia, a little bit behind the UK, but certainly not at the top tier of the US at 28.5, or Spain at 39.7 deceased donors per million.

In terms of where we've seen improvement — this is just highlighting some of the things that you may have already heard — that deceased donation from brain-dead donors, in red here, has really been fairly stagnant over the last number of years. But what we're seeing is an increase in deceased donation after cardiac or cardiocirculatory death. In fact, most of the growth, if not all of it in deceased donation, has occurred because of the introduction of this form of donation across the country.

This is just showing regional differences in deceased donation by province in terms of donation per million. A number of years ago we set ourselves a target of 22 deceased donors per million population. And you can see that in some provinces — BC, Ontario, Quebec, and in Nova Scotia — we're starting to approach those numbers. And we know in 2016 we're around 20 donors per million, at least in these provinces. But there is great variation across the country and so we're trying to understand some of that variation which I'll come back to in a second.

This is just again to reflect what's been going on in Saskatchewan. We've seen a fairly plateaued level from 2007 to 2011, with a drop-off in 2012 and some recovery by 2015, and you can see a little bit of DCD activity taking place in 2015. I can comment that this is no different than what I've seen happen in Manitoba, in our next-door province.

Now donation . . . We think about the opportunity of all deaths to be organ donors. But what I want to highlight in this diagram, and we've looked at this at a national level, at understanding where are the opportunities. And if you think about all deaths in the population, well the first thing to be an organ donor, you actually have to be in a hospital system on life support. So that all of a sudden now restricts who can be an organ donor. Beyond that, you need to be ventilated on a respiratory machine. Typically, these are brain-injured individuals. People dying with cancer typically are excluded from being a donor for obvious reasons. Brain injury is not that common an occurrence.

Then we get down then to the level which we would call as potential donors, and these are the donors that we want referred to the organ donation programs. Whether they're referred or not, as referred potential donors or whether they're eligible donors after medical assessment, that really depends on local standards. What are the policies of your province? What are the policies of your health authorities? What are the policies of your organ donor organization? And that will dictate what proportion actually get referred.

Once they're referred, they have to be approached, discussed, find out what the wishes of the individual were if they were known or discussed with the families. Once consent is obtained . . . And again we're sort of funnelling down because at every stage we're seeing drop-out. Once we have a consented donor, we do a thorough evaluation according to national standards for whether or not, after multiple imaging and diagnostic testing, whether there's any medical issues that have arisen that would exclude them from being a donor. Most notably that might be an infection or an undiscovered cancer that we didn't know that they had.

Then we get down to actual donors and then, with the actual donors, sometimes we're not able to utilize the organs for various reasons that we can go into after. But then ultimately, you get down to utilized donors. And so of all deaths that are occurring in this country, less than 5 per cent could be a potential donor. And from neurologic determination of death, that number was 1 to 2 per cent. Now that we have DCD, we're saying less than 5 per cent. So less than 5 per cent of all deaths are ever going to be a potential donor within the system. And understanding the dynamics of what's happening in your province in this type of a pyramid is actually very informative to understand opportunities for improving donation. Next slide.

Now to try and optimize eligible donors, we've gone through a whole host of detailed reports as a nation where we've identified leading practices. Before Canadian Blood Services it was the Canadian Council for Donation and Transplantation bringing experts from around the world and from across Canada together to develop leading practice policy recommendations, and then since the inception of CBS taking over this file in 2008, ongoing leading development practices. And as we've implemented these practices, that's where we're seeing provinces start to see gains in their donation activity. Next slide.

This is really a report card or a dashboard of red, yellow, green of where different provinces are at in implementing these policy recommendations. And as they've been implementing them and going to green across the board, that's when we've been seeing increases in activity. So I'll just note BC, which had a number of years ago been at a fairly low rate, really in the last few years have implemented aggressively these policy recommendations and have seen marked increase in their deceased donation activity so that now they're on par with Ontario and Quebec, which they had never been before.

I will speak on behalf of Manitoba in terms of my own experience. These key elements, and I want to highlight them — mandatory referral, donation physicians, implementation of leading practices around neurological determination of death, implementing a DCD policy — if you do any one of these things on its own, it's not going get you the increases that you expect. I can tell you that in Manitoba we implemented donation physicians five years ago, but we didn't implement DCD and we didn't implement mandatory referral at the same time for some logistical reasons and some policy-based reasons. And it was only once we implemented these policies in 2015 that we've really seen these things all work together.

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. 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. Next slide.

In terms of turning now to a living donation, Canada as a whole is again sort of middle of the pack at 15.7 living donors per million. And our benchmarks countries, Australia, were above that, about on par with the UK and below where we'd like to be, with the US at 18.8.

What is interesting in Canada is that while we're at 15.7, this is a fairly static level of living donation in the country. We've seen it hold itself. It's gone down a little bit, but it's overall held. Whereas if I compare that to the United States or Australia, they've seen a drop-off in their living donation rates significantly, compared to what we've seen in Canada. Now in part we attribute this to the implementation of an innovative program like the kidney paired donation program, where it's now accounting for 13 per cent of all living donations in the country, bringing in donors who previously would have been excluded from living donations. So we feel that's a key national program which is not present in the US. We're actually ahead of them in that regard.

When we look across the country, again we see regional variation in living donation trying to hit our target of 20 living donors per million. Some provinces, most notably . . . If you go back, Kim, or I don't know if you can go back. I'll just highlight. BC is above our target and they've put a lot of emphasis, and they did put a lot of emphasis on their living donation program. Because their deceased donation program had been lagging, they put a lot of effort on living donation. And now they're seeing the net gains because they've got emphasis on both together, so they're above target.

[12:15]

And we'll go on to the next slide. This is just showing what's been going on in Saskatchewan. Saskatchewan is participating in the KPD [kidney paired donation] program, and that's assisting in trying to maintain the living donation program here. Next slide.

What we've learned from BC and some of the other high-performing countries though is that in putting resources into accelerating workups of living donors so that we don't lose those living donors because it's taking so long to get them worked up, that there's other issues that come along. Life comes along. That opportunity when they were willing to donate is now gone because it's taken too long for them to get to that living donation event.

Having appropriate support pre- and post-transplant for both the donor and the family so that they feel cared for through that process, and again national programs to support living donor activity like I've already mentioned. And importantly, access to testing and medical diagnostics which really form the basis for working up a living donor. We need those activities to be available and resourced so that these living donation opportunities can be realized. Next slide.

In terms of transplantation, I've already alluded to that there's been a 23 per cent increase overall in transplantation. This is largely attributed to the increase in deceased donation. Next slide.

Again if you look at both kidney transplants from a point of view of deceased and living donors combined, we see regional variation across the country, and our target here is at 44 kidney transplants per million population. Next slide.

Saskatchewan had been at a fairly high rate back in 2008. There was a decrease in 2010, not because they weren't doing it at all, but the patients were being referred to Alberta at that time because of the need for support of the surgical services and recruitment of a surgeon. So this is in no way saying there wasn't activity occurring in 2010. There was transplant activity; it was just being done out of province at that time. Next slide.

I do want to highlight . . . This is core CIHI [Canadian Institute of Health Information] data from 2016 referring to 2014 data, just to give you a sense of the total burden of kidney disease in the province and compare it to the other western provinces and Ontario. You can see that Saskatchewan in the lower number here at 1,090 end-stage renal disease patients per million population, is the burden in this province. Alberta is very similar at 1,059 patients living with end-stage kidney disease. Manitoba is a lot higher. A lot of that is First Nation-based in our province. Ontario is higher because of an aging population that they've seen in their province.

What I do want to highlight here for you though is how provinces are resourcing and dealing with the treatment of end-stage kidney disease. And if we look at Alberta, it's about 50/50 of patients with a transplant or patients on dialysis. And you can see by comparison in Saskatchewan, more resources are being spent on dialysis care compared to transplant care. And if you think about it in terms of the cost burden for the health system, that means you're spending a lot more money looking after end-stage renal disease patients because you've got the predominant majority on dialysis therapy. Next slide.

The benefits of kidney transplants. This is a fairly important slide from the perspective of the patient. We all know that a transplant gives you improved quality of life, but in kidney transplant, it actually doubles your life expectancy. So if you're living on dialysis, if you get a transplant, you can expect your life expectancy to double. And that's true no matter what your age is. This is United States-based data, but even up to the age into your 70s, if you have a transplant, you will live twice as long compared to staying on dialysis. So it is truly a life-saving therapy to get a transplant. Next slide.

In terms of cost, dialysis cost averages about $50,000 per year per patient, so a fairly expensive modality. A kidney transplant in the first year is about on par with the cost of dialysis. But beyond the first year, the cost advantage of a transplant is marked. You're spending on average about $10,000 per patient per year for drug therapies and ancillary care around that patient.

So the main point here is that from an economic point of view, not only do you have an improved quality of life, do you have an extended life, but you have a much cheaper way of delivering a service to the patient in terms of the burden on the health system. Next slide.

So with that I'm going to turn it back over to Kim to finish.

Ms. Young: — So just in summary then, a few important points that we want to link home. 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. DCD and NDD [neurologic determination of death], that's been described by multiple people at this table already, but they're the key features of bringing the most donors possible.

The donation specialist network and team, it's supported at the national level by Canadian Blood Services bringing this group together. It can be implemented in many ways, and you heard some of those ideas today. There's not one specific pattern, but it's around the leadership and the culture change that needs to happen in those organizations. Many of these leaders are reporting regularly to the CEO [chief executive officer] in their sites so that that partnership and that accountability is embedded in the cultural change.

Living donation, Dr. Nickerson described the capacity. People need to be assigned to this role. They need to ensure that there are people that can actually carry this out. 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. And again, testing is important, but once you've done all that workup, if you don't have an operating room available to move them into, you lose their interest as well. And believe it or not, that's a serious challenge. So we can manage traumas into the O.R. [operating room]. These are important cases too. These are donors that are willing to give that gift that we've already seen saves lives quicker and helps the health system save dollars, yet we're not getting the cases into the O.R. in a timely way. So that's an important focus.

Transplantation again. In the past, lack of reliable data to base on your outcomes. We need to make sure we're giving the best treatment possible. You just heard a description by Dr. Nickerson that the best treatment modality for kidney candidates is transplant, yet we're investing so much more in the dialysis opportunity which presents a much decreased lifespan for those patients. So taking a look and understanding the treatments we're supporting is so important.

Varying the criteria used to list patients, allocate and accept organs. We need to do this as a country at the national and provincial levels, and so we're working on that in ongoing work. That will be the day-to-day work of our organization, together with Saskatchewan, forever. That's how other successful systems are working. The system itself, improved strategy with clear targets and measures is so important that whatever strategy this table and others create has well-described targets and measures to track improvements because it's not linear. You're not going to see a continual growth even with rapid adoption of leading practices.

We see that the sustained focus is hard. Sometimes you slip back — Dr. Nickerson described Manitoba — but it takes the complete harmony of all the improvements and time to allow them to embed. Spain didn't get to 40 per million in 10 years. They didn't do it in 20 years. They did it in 30 years. So it takes time to create these changes, and it takes the focused leadership as well to move those forward.

National, international best practices do work. We can build what we've described to you here today. The donation specialist is the best from Spain. The required referral is the best from the US. And when you looked at that map that Dr. Nickerson showed you, that was the best from the two places we want to benchmark in the world. And it can and it does work here in Canada.

So in closing, I want to suggest that we're here to work together with the Saskatchewan program. We are very much a part of what you fund and support. And we continue to want to offer more in the areas of many of the topics that were introduced to you previously we haven't touched on, like presumed consent. We've done deep analysis of those topics and would be happy to come again or provide to you other submissions to help guide your thinking. Thank you for your time.

The Chair: — Thank you very much for your presentation. We'll start with questions now with Ms. Rancourt.

Ms. Rancourt: — Thanks for your presentation. Health Canada has indicated that they're moving towards behaviour-based screening. So can you highlight how this could mean some changes for organ donation rates, and is Saskatchewan involved with the discussions on a national level?

Ms. Young: — So I'm trying to link those directly. So the behaviour-based donors, looking at the evolution in the blood system, for example, is that where we're . . . So we do definitely in the cells, tissues, and organs regulations have the ability to look at the potential donor. The organ donor is tested immediately and those testing criteria are shared within six hours with the program.

We also are evolving our acceptance criteria. So for example, you'll hear about some reports of the first HIV [human immunodeficiency virus] positive to an HIV positive candidate. So similar to how they're evolving the blood system, the cells, tissues, and organs group is continuing to evolve the guidance, documents, and the regulations. And yes, there are representatives from across the country on those technical committees. I'm not sure who represents Saskatchewan. I do sit on the technical committee myself, and so I know there's a good group of people.

Ms. Rancourt: — I don't know if you're able to answer this, but I've heard that there's different requirements for someone to be a tissue donor than an organ or blood donor. And so could you explain why there would be a difference between their criteria?

Ms. Young: — So for tissue, one of the big differences that you may have heard about is age. And let me give an explanation there. That does vary by country and certainly even by province here. When you've got the ability to accept that gift of donation from any donor, the importance is that you explore it and you look at the rule-in/rule-out criteria. And many of them are the same for organs or tissues. But in the case of tissues, when the bank has a lot of product available, then they can in fact start to decrease the age criteria because it's assumed that the younger criteria might be a better tissue sample.

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.

So there's a lot of work done to really understand the rule-in/rule-out criteria, which is why we need donation specialists or members of the donation specialist team to really work with your community and not to make any assumptions about rule-in/rule-out by tissue, by organ, but rather understanding the system today and making those offers. It's amazing. We've had, in Alberta, a very elderly, over 75-year-old person that transplanted a liver that still worked for many, many years — many, many years. So in the past, they would have ruled that out.

So the system's evolving. Science is evolving, and we want the experts to make the choices. Does that answer your question?

Ms. Rancourt: — Yes, thank you.

The Chair: — Mr. Docherty.

Mr. Docherty: — Thank you, Mr. Chair, and thanks for the presentation. It's very informative, and I appreciate, number one, the fact that you've put together such a great presentation.

I have a particular question in relation to, you talked about Spain as a gold standard in relation to donation rates. And I'm looking at slide 14, which is the international deceased donation rates 2015, Spain is number one. And if you go, in comparison to slide 22, which is the worldwide actual living organ donors, Spain doesn't show up. Now I looked at slide 23 and I saw Spain at just under 10 per cent, figuring that they'd be somewhere around Australia. And I'm wondering why they were, why they didn't show up on the worldwide actual living donors piece.

Mr. Nickerson: — So maybe I can comment on that. Spain, because it's performed so well in deceased donation, really has not made living donation a priority. So you can look at each country and you can see where they've put the emphasis in their donation resourcing. And in Spain's case, they put all of their emphasis in creating this culture of donation and working out what are the key instruments that allow for deceased donation to flourish. Living donation then became a very low priority for them.

In countries that actually do well, they're investing in both, right? So Spain has recognized that. If they want to get themselves to the next level, especially in terms of kidney donation, they need to move in their living donation activity, and that's . . . a lot of emphasis is going. So you can see that uptick now in Spain where it had been very low.

Mr. Docherty: — Yes, thank you.

Ms. Young: — . . . you can build on that in Canada and look at programs that had very high deceased donor rates had very low living donor rates, and they're actually flipping that around now. So British Columbia is a perfect example there: for many years the leader in living donation, but did not have very high deceased donation rates until they applied those top four pieces that Dr. Nickerson described. And now we've seen their full rate for donation increased because of the combination of a very successful living donor program and now one of the nearly most successful deceased donor programs.

Mr. Nickerson: — Correct. And maybe just the same slide, looking at it and realizing that Quebec has put very little emphasis on living donation because they had such a high deceased donation activity. So you know, the need is to raise votes on both sides and not just focus on one area or the other.

[12:30]

Mr. Docherty: — Yes. Can I just quickly follow up? But in relation to Saskatchewan then, where should we focus right now in order to balance both deceased and living donations?

Mr. Nickerson: — Well I was just listening to the Saskatchewan presentation. I think their focus is to focus on both, in honesty. Because remember, living donation is going to help patients waiting for a kidney or a liver, rarely lung — occasionally lung, but rarely lung. It's really kidney, number one, and then liver. To get access for the population of Saskatchewan to heart, liver, lung transplants, that comes from multi-organ donors which are deceased donors. So I think, you know, if we're focused on kidney only, I'd say it's both. But for multi-organ, it's really deceased donation.

Mr. Docherty: — Thank you.

The Chair: — Ms. Lambert.

Ms. Lambert: — Thank you. I'm looking at the Canadian Transplant Registry, and my question focuses on that. So you note that there's a national agreement to share kidneys. So is it your plan, your long-term plan that we expand that national agreement to other organs? And then you made some mention to an informal gentleman's agreement, and so I wondered if you could expand on that a bit.

Mr. Nickerson: — Sure. So that's a great question, a great insight. So for sharing of kidneys, right now we're sharing kidneys for the highly sensitized patient, those very difficult-to-match patients. Because obviously there's a great demand in your province for kidney transplant people on the wait-list, similar to as it is in my province.

So for kidneys we're really focused on the KPD program, the kidney-paired donation and the highly sensitized. For the other organ systems — heart, lung, liver — many of those patients end up being listed in other programs. I suspect most Saskatchewan individuals looking for a liver, heart, and lung are listed in Alberta, but I might be wrong. And the provinces with those programs have as, Ms. Young alluded to, sort of informal agreements of how they're going to share hearts and how they determine who is the highest status heart recipient, who is the highest that are liver recipient, etc. for the other non-kidney organs. We're in the process now of working with those communities.

Canadian Blood Services has created advisory committees for heart, for liver, working on bringing those informal agreements into formal policy and, once in formal policy then, having them operationalized through the Canadian Transplant Registry. So the Canadian Transplant Registry today provides a transparent wait-list of who is in need of these organs. The rules are applied fairly, I would say, fairly regularly and in a standardized way. But it is informal, as opposed to formalized, and we really do need a formalized system. I think you've hit on a key point that that does need to be developed, and the community is committed to that and CBS is committed to supporting that.

Ms. Lambert: — Thank you.

The Chair: — So that opens up just one quick question for me, because it's something we all struggle with across all our jurisdictions, is with all the different privacy concerns out there. With Canadian Blood Services, if they went . . . being the national donor transplant list, how do you expect to meet all the different privacy levels across all the jurisdictions? Is that part of your discussions in the informal process that you're working on right now?

Mr. Nickerson: — So I can start this answer, and maybe Ms. Young can add to that. So right from the inception of the CTR [Canadian Transplant Registry], when we launched the kidney-paired donation, which was the request of the provinces to CBS to initiate as the first operating registry, right from that point we actually started privacy discussions, data sharing discussions, and patient consent discussions.

So everybody who's on the registry has given informed consent to be on the registry, and each province is in discussions with

CBS to a uniform data sharing and privacy agreements. And as you alluded to, these are complex because each province has slightly different . . . under their provincial jurisdictions, of being in charge of health care requirements around privacy. And so we're working diligently with our provincial counterparts, with the Canadian Blood Services legal group to formalize again the agreements around this. I'm not sure, Kim, if you want to emphasize anything.

Ms. Young: — Right. So many are in place already but need to continue to evolve. And as you're looking at your legislation and your privacy considerations, we'd be very happy to talk to you about some things other provinces have done to ensure the road is very clear for the collection of data, which is so important for you to have in a regular and routine way, and also for us to establish and maintain the features of appropriate data sharing.

So we're very committed to this. We do this for the blood system, and we're certainly working on this with every different province. And this again will be our ongoing work as we continue to evolve and make these systems available. The same as other countries around the world have achieved this, I know we can get to this.

The Chair: — Well thank you very much for your presentation. Seeing there's no other questions right now, we're going to take a recess until . . . Well before we do a recess, we're going to make sure we table your document HUS 21-28, Canadian Blood Services regarding organ donation inquiry.

So again, thank you very much. We'll take a recess until 1:15 p.m.

[The committee recessed from 12:36 until 13:18.]

The Chair: — Good afternoon. We're back in session from our recess. I'd like to introduce our committee members that have swapped out this afternoon. We have Ms. Campeau sitting in and Mr. Buckingham sitting in. So with that, welcome back to our other committee members.

Our next presenter is Cheryl Olson. I'd like to welcome you to the committee today. Before you begin your presentation if you could introduce yourself . . . and I'll skip over the next part. If you have anybody show up to present with you, please introduce them, and if you're speaking on behalf of an organization, please state your position within the organization represented. And if you have a written submission please advise that you'd like to table the submission. Once this occurs your submission will be available to the public and electronic copies of tabled submissions will be available on the committee's website.

Once your presentation is completed, the committee members may have questions for you. I will direct the questions and recognize each member that is to speak. Members are not permitted to engage our witnesses in any debate, and witnesses are not permitted to ask questions of the committee. Our agenda allows for a 30-minute presentation, followed by a 15-minute question-and-answer period. And if you would please proceed with your presentation.

Presenter: Cheryl Olson

Ms. Olson: — Thank you very much. First I just want to have a little disclaimer here. I was sitting back watching the previous organization and I'm just me. So I'm sure that the organizations you hear from will have much more focused ideas and much more updated stats than what I could find when I did my research online.

My name is Cheryl Olson and I'm also known as a statistic. Thank you for giving me the opportunity to speak to you today and give you a few ideas on organ donor awareness. I'm thrilled to see this being discussed and a plan being formed to improve donation rates within Saskatchewan.

I'm going to start by telling you a little bit about my story and what brings me to be here today. Back in 1999 I was kind of like the general public and I thought organ transplants only happened if you were born with a medical condition or if you had poor lifestyle choices. But that changed, like I said, in 1999 when I got flu-like symptoms and I just became very, very ill. I was 31 years old at the time, a wife and mother of two young kids. They were ages three and six. A virus attacked my body and it nearly killed me a couple of times. I ended up in the hospital with triple pneumonia in both lungs and a 50/50 per cent chance of surviving. I tell people now that it was like running a marathon that you had never practised for, never trained for. Each breath was a painful struggle.

As the hours passed, it became obvious I was going to make it. And then a few days later we hit the second brick wall and my platelet levels dropped dangerously low, and they thought I might have leukemia and I was also at a very high risk for a stroke. So the plans were made to do a spinal tap, but before they did that they gave me a transfusion of platelets, and thankfully that seemed to cure the issue.

Then while I was still in the hospital, not long after that, it was discovered that my legs were full of blood clots, along with one in my liver and what they determined was one in my heart that they originally thought was a tumour. I was treated with blood thinners, and once again we all breathed a big sigh of relief that I was going to be okay.

So after two weeks in the hospital they allowed me to return home. But unfortunately the virus wasn't finished with me yet, and after two weeks at home I was back in the hospital in Saskatoon here with heart failure. My husband was told that many people in my situation do not survive.

Within two months of first getting sick, I was on life support in Edmonton with less than 24 hours left before my husband was going to have to make a difficult decision to let me go — I'll get through this — or he was just going to be told that I was too sick to survive a heart transplant surgery.

So this is where awareness comes in to my story, because awareness really saved my life. My story was covered heavily in the media with headlines like "Young wife and mother needs a heart transplant to survive." It was the lead story on all the news broadcasts across Canada. It was front-page material on many newspapers, and my family and doctors were interviewed. My story was basically front and centre, and it was very hard to miss. And that's very important.

A young man named Adam was watching the news one night with his mother, and my story came on. They were talking about my desperate need for a heart. When the story was over, Adam turned to his mother and he said, wow, don't you wish there's something you could do to help that family? And two days later, Adam was injured in a fatal accident, and he became my donor. He was 21 years old.

When his mother was approached about donating his organs she said, yes, as long as the young mother gets his heart. Of course they couldn't guarantee that because everything has to be a match in many ways. But because of the media getting my story out there for people to hear, and because of what Adam said, she agreed to organ donation.

After 133 hours on life support, my family's prayers were answered and I received a new heart. Just a side note, that was a record for the doctor that puts patients on life support. He had never had a patient that was on it that long survive.

And I wish I could say that Adam's heart and I were still getting along fine all these years later, but I can't say that. We had a great eight years together before I started having problems. I found myself being told that I needed a second transplant due to chronic rejection. And that is definitely not something that a recipient ever wants to hear, that you have to go through it all again.

Shortly after my nine-year anniversary with Adam's heart, my second miracle took place and I received a heart from a beautiful 16-year-old girl named Lindsay on October 15th of 2008.

Over the years, I've been the subject of a few mini-documentary type programs and I've done public speaking, radio programs, and interviews about organ and tissue donation, and I'll even be on the back of the city buses in October.

So I'm here today to speak on behalf of myself and every recipient I know personally or in my online groups, and to share the ideas that are often discussed within our transplant community. And I should note here that when I use the term organ donation, I'm focusing mostly on deceased donations. There will be a small part on living.

I will start with one important demographic that we feel we should strive to inspire is our youth. We have a captive audience every day that they are in school. And I understand they are underage for registering without parental consent, but they are the future of our province and of our country, and if we can get them talking about organ donation then over time it will become mainstream within our society. I will also point out that both of my donors were young and had not given much if any thought to organ donation.

So how do we get our youth talking about it? We go to the schools. For example, we set up a program that involves recipients and a representative from the transplant program to go and speak to a grade 9 health or science class one day each semester. I feel a classroom environment would be preferred over an auditorium seeing as it would encourage more questions and conversation. Every student who comes into that classroom that day will hear a recipient's story and can take home an information sheet that they can go over with their families. The information sheet can address many of the questions and myths surrounding organ and tissue donation. It gets the discussion happening, and ultimately and hopefully everyone's personal wishes will be known by the time they go to bed that night.

My next suggestion is one that I think is kind of fun, and I'm going to tell you just a little personal story to get into it here. About a month prior to me getting sick back in 1999, my husband and I attended a Roughriders luncheon here in Saskatoon, and with the then coach Cal Murphy. And in case you weren't aware, Cal Murphy was a heart transplant recipient. He started his speech by introducing a young man in the audience who was a kidney recipient that he met in London, Ontario during his recovery. He encouraged everyone there to consider being a donor and to talk about it with their families.

Sometime within the next week or so, my husband brought it up and we talked about it. It was a very short conversation; we just looked at each other and said, yes I'm willing, yes I'm willing. And then he said, what about our kids? And I said, I don't want to talk about that. But he said, we have to talk about it. And so I said, of course we would but I don't want to talk about it. And little did we know, of course, that we were about to embark on our own transplant journey and that my life would be saved by organ donation. That's the end of the story. Back to the fun idea.

Saskatchewan is full of crazy Roughrider fans. I am one of them. Many have probably abandoned the bandwagon this year, but a partnership with the team for an awareness campaign would be fantastic. I do remember seeing a billboard a few years back with a player encouraging organ donation, but I never saw or heard anything else other than that one billboard and I think it was in North Battleford.

A campaign like this could be huge. You can involve volunteers at games to hand out information and to talk to people. And if we're lucky enough to get a provincial registry, which I'll talk about later, then you could get, for example, an autographed jersey. Have people come, sign up, put their name into a draw. It would get a lot in one game, let me tell you. Get high-profile players involved in commercials that would air during the games. And I'm sure there are many other ideas to be had that can involve the team.

But while we're on the subject of commercials, I'd like to encourage you to make commercials without Riders as well. But they need to be emotional, emotionally charged, something that is going to pull on heart strings instead of just a bunch of words encouraging people to consider donation. People's emotions need to be tugged at in order for them to remember something and respond to it.

Now this is the part with the living donation. At the request of a personal friend, I'm going to take a moment to touch on one aspect of awareness that is often overlooked at least within the general public. I know it's been discussed in other organizations in front of you already. It is rare that living donation is talked about. She said it would be great if you could un-scarify the topic so more people could, would consider it.

This friend's husband is in need of a kidney and she is hoping to be a match. She has mentioned that she can't find much information about what to expect for the living donor, and people need to know that they can donate kidneys and lobes of lungs and parts of your liver. And they need to have a clear understanding of how that will affect them in every aspect from the testing leading up to it, to the surgery, and to living, recovery and living with that decision for the rest of your life.

[13:30]

Another area we should focus on is the hospitals and the medical staff. Before moving out of the city, I was part of a Saskatoon transplant support group. From time to time, we would arrange to go to hospitals and speak to the nurses and doctors most likely to be dealing with patients with severe injuries. We called these events Thanks for the Asking. We put a face on the world of organ transplants by sharing our stories with them and thanking them for what they do every day. We encouraged them to make sure they don't let any possible donor opportunities be missed so that every possible life can be saved.

Within Saskatchewan, we have many rural medical facilities. How equipped are they to identify potential donors and keep them viable until they can be transported to a larger facility? Perhaps this is a matter that could be addressed at the Saskatchewan Medical Association's annual meeting, or the College of Physicians and Surgeons.

Another avenue to explore would be following the example of Ontario. Two years ago, they put a spotlight on the issue of organ donation and began to report hospital statistics regarding the notification of potential donors to the Trillium Gift of Life Network. TGLN handles both the waiting list for those in need of a transplant, and the provincial registry of those willing to be a donor after death. It should be noted that people are asked about their wishes when they renew their driver's licences, but they also have the option of going online and signing up there as well. However, we tried that. With either BC or Ontario's program, you have to click through at least five different pages just to get to where you are going to go. I'll address that later too.

According to the president and CEO of TGLN, the numbers have been going up since these programs have been put in place. Ontario now has a 94 per cent provincial average of reporting, meaning that 94 per cent of the time when there is a donor situation, the TGLN is contacted. However, that does not mean that a donation happened in each of those situations.

I couldn't find what Saskatchewan's reporting average is, but since we have the lowest rate of donations, I assume we are lower than that. What I did find were the numbers of donations from 2015. In 2015, there were 10 multi-organ donors and 45 cornea donors in Saskatchewan. Those are low numbers. And we must shine our own spotlight here at home by posting hospital stats and reporting possible donations, and by educating the hospital staff.

At this point, I am going to change things up a little bit and move away from awareness to another option that could help increase organ donation.

In discussions with other transplant recipients and related individuals, a prevalent theme I hear is that we need to have a provincial online registry where people can register themselves as willing donors. And of course, again I mean willing donors after death.

Every province has a different system for indicating one's wishes when it comes to donation. Alberta, BC, Manitoba, and Ontario all have a provincial online registry. Why don't we? And how can it be done?

Here are a few ideas: develop a website where people can go to sign up. The only problem with this is that it demands action on the part of an individual if they even hear about it. And that type of thing usually ends up in the I'll-do-it-later category and is then forgotten about. For example, British Columbia has a little over 1 million registered willing donors but their population is almost 4.7 million people. So obviously, they either aren't hearing about it or they aren't taking action.

So how do we get around that problem and still have a useful registry? One possible solution is to require everyone that does a transaction through SGI to answer one simple question: yes or no to organ donation. If they answer yes, then the information could be sent to Sask Health or directly to the Saskatchewan Transplant Program and entered into a registry that is updated daily.

Another option would be to include a line on the Saskatchewan tax return forms. It's not rocket science but either of these methods could be efficient to start a registry.

I should add here that having a provincial registry would create excellent opportunities for volunteers, who would probably mostly be recipients, to get out into the community by attending functions and getting people to sign up if they haven't already. And believe me when I say that the transplant community is willing to get involved.

Now I have shared with you some ideas about awareness on a provincial level. So please bear with me while I go outside the provincial box for this next point I'm going to make. It is a point that is on the top of the list for things recipients would like to see happen, and the only way it's going to ever happen is if we educate the lawmakers.

Recently Bill C-233 asking for a national registry to be developed was quietly voted down by a margin of 171 against to 131 in favour in what appears to be a partisan decision, a ruling that most definitely will affect many lives. One of the reasons for voting it down is that the Canadian Blood Services is currently involved with the organ transplant program and they feel that this is adequate. But unfortunately I don't think that it is. Now don't get me wrong, because I think that what the Canadian Blood Services does is fantastic, and no transplant surgery could take place without what they do and without what they provide. And also from hearing them speak earlier, I believe that perhaps they're already possibly moving in the right direction.

As one MP [Member of Parliament] said regarding Bill C-233:

> In principle, it appeared to me something we should send to committee. The idea of the bill was to improve organ donations in Canada and hopefully increase organ donations. That is a worthy goal. Whether that mechanism is the right one, I have no idea, but it deserved further study.

Thanks to that vote, it will not receive further study. I realize this was on the national level and not provincial, but I'm going to speak about it anyways because the goal here is to raise awareness and increase donations, which is what we feel a national registry would do. And let's face it, the need for an organ donation does not know provincial boundaries.

At the very least, this province and this country needs a national registry of willing donors. But I'll take this one step further and suggest that what this country really needs is to follow the example of many other countries and develop a presumed consent or opt-out program.

Canada has one of the worst donation rates in the developed world. 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.

According to a 2014 report by the International Registry on Organ Donation and Transplantation, Canada had approximately 16.5 deceased donors per million population, trailing way behind the world leader Spain at nearly 36. Spain instigated presumed consent in 1979. In 1979. That's 37 years ago. Another example is Belgium, who passed their law in 1986. They had two similar transplant centres, one in Leuven and one in Antwerp.

Leuven switched to presumed consent with the passage of the law and in three years its donation rates climbed from 15 to 40 donors per million, while Antwerp did not change its policy and only maintained previous levels.

In Austria presumed consent became law in 1982 and by 1990 the rates of donation had quadrupled to the point where the number of patients awaiting kidneys nearly equalled the number of kidney transplants performed.

I think you get the picture on that, but I do have a list with about 16 other countries that do presumed consent.

Saskatchewan's leaders need to follow in the footsteps of the Hon. Tommy Douglas who led Canada in the development of a national health care program and pushed for what is best, not only for our province, but for the entire country. I feel there is no reason why Saskatchewan can't be a leader on this subject.

Can the opt-out program begin with one province? Well according to the words Health Minister Jane Philpott used when defending the death of Bill C-233, organ donation is a matter that is "under provincial jurisdiction." So that tells me that we can consider forming any kind of provincial program we feel is best for our province. So why not let presumed consent or opt-out programs start here?

Let's take this presumed consent or opt-out option to a more emotional level and think about the families who, while in the middle of one of the most devastating moments of their lives, are approached about donating the organs of their loved ones. I'm sure everyone in this room has someone that they love very much — a husband, a wife, a sister, a daughter, a son. Imagine, if you can, possibly being asked to make a rational decision while experiencing that kind of grief and shock that comes from being told that your loved one is gone, and usually in a very sudden circumstance.

Neither of my donors had indicated their wishes regarding organ donation other than what Adam said to his mother, so my very life hung in the balance as doctors waited for these devastated families to say yes or no. Presumed consent would do away with the need for that difficult conversation. Even if we don't have presumed consent, a registry of some kind would take the weight of the decision off of the family.

I truly feel that our society is ready for presumed consent, and if you want to test that theory, get the discussion started on social media. We see time and time again that social media gets people talking about issues and makes things happen. In fact you didn't hear about Bill C-233 because, at that very time, social media was in an uproar about the changing of our national anthem wording.

In the meantime, we need to put people in front of the lawmakers that can tell their story and explain what organ donation has done for them. We need to put people in front of the lawmakers that can share their story of sitting and watching their wife, husband, child, or parent die because they didn't receive an organ in time.

I personally would fully embrace the opportunity to share my entire story — you got the nutshell version — and my passion on this subject, and then challenge any person in that room to explain to me why they would not support presumed consent or, at the very least, a national registry of willing organ donors. And I dare say that there's not a single person in that room that could look me the eye and tell me they wouldn't support it.

Organ donation not only saved my life, it saved my family. It kept us whole. I never get through this. It kept a wife and a mother in the home. So far I've had an extra 17 years of life. During those years, I have watched my son learn to ride a bike and listened to my daughter sing. I have made school lunches, attended school plays and parent/teacher conferences. I have been there for first crushes and first heartbreaks. I have posed with Mickey Mouse alongside my family. I have proudly and gratefully watched as both my children graduated high school. I have wrapped Christmas presents and baked birthday cakes. My kids, who were three and six when this journey began, are now 20 and 23. And I've celebrated 26 years of a wonderful marriage with one of those guys back there. And I've made many memories and I look forward to making many, many more.

So to you, the committee, I beg you and I challenge you to be aggressive with your plans for organ and tissue donor awareness within our province and within our country. You have the power to make change and that's a power that many of us wish that we had. So on behalf of every person on a waiting list right now and every recipient like myself that might be told their transplanted organ is failing, please use your power wisely and as though the life of someone that you love depends on it. Thank you for your time.

The Chair: — Thank you very much for your presentation and speaking from the heart. Mr. Docherty has a question.

[13:45]

Mr. Docherty: — Thank you, Mr. Chair. Cheryl, I wanted to start by just thanking you. Thank you for bringing your story forward. And secondary, never apologize for showing emotion. You did a fantastic job of articulating what you think the system requires.

It's interesting. If there was a national online registry, that's one piece of the puzzle. If we looked at the second piece that you talked about and that was the presumed consent or opting out, we've had other presentations that have talked about research might not necessarily support that and in particular, the country of Spain where everything else they attribute to the success of the deceased list.

What do you think in . . . How would you suggest that we would go about performing an opt-out or presumed consent piece within this province?

Ms. Olson: — Within this province?

Mr. Docherty: — Yes.

Ms. Olson: — First of all, I think it would just, I mean it would have to come down to the point where it would be made into some sort of a law basically. And I know you're going to have people in the general public that are going to not be happy about that but that's why you have the opt-out option. The way things stand right now, people have to opt in and they just don't because people don't think about organ donation. People walking around on the street don't think about it unless somebody that they know is in that circumstance.

In order to form one, I think it just basically needs to get put before the lawmakers and then it can just be, like I said, instead of having people opt in at SGI, for example, or on the tax returns, you can opt out. And people are going to take those steps. If they don't like something, if they feel that their rights are being violated, then they're definitely going to go and say well that's not for me, click. But, you know, nine times out of ten they're probably not going to opt in.

So I'm not exactly sure, I'm not up on how these laws and things like that get passed. That's probably . . . someone else can answer that better than I can. But in that situation, it's something that needs to get front and centre in front of the lawmakers, the people that can make the change.

Mr. Docherty: — Just to follow up. Yes, and that's a very good suggestion. There are examples. We presently have a few within the province and one that comes top of mind would be, for instance, how easy it is to tick off the box in relation to your school taxes.

Ms. Olson: — Right.

Mr. Docherty: — I mean there's the box.

Ms. Olson: — Right.

Mr. Docherty: — Right. Which one are you going to support? So I mean there are boxes and there's many more than that but yes, thanks for that. I appreciate you being here and thank you for that.

Ms. Olson: — Thank you.

The Chair: — Ms. Chartier and then Mr. Buckingham.

Ms. Chartier: — Thank you so much for your presentation. As a mom, I really appreciate that you've gotten these extra years with your kids.

Ms. Olson: — Me too. Thank you.

Ms. Chartier: — So this maybe should have been something for the Blood Services this morning. I'm regretting not asking this. I think I have some misunderstanding. So CBS, it sounds like, has a national registry but is in the process of taking it, we were told this morning, that within a few months it would be even more robust. But clearly that hasn't met . . . I didn't know about that prior to sitting on this committee. But maybe you can add a few words.

Ms. Olson: — Well what I found when I was doing my research online about the Canadian Blood Services is that they have three different registries but none of them are for, like, people who sign up saying yes, in the case of my death, please I would like to be an organ and tissue donor. I don't believe that . . . They don't have that because they deal with things more on a national level and everything else is done provincially. You know, every province has a different system for indicating your wishes.

Now I think I heard also while I was sitting back there that they are moving in that direction, which I'm really, really happy to hear about. But I don't know even if what they were talking about was willing donor registry. I didn't quite catch that when they were speaking so I would have to look into that more as well.

But from my understanding, they have three different registries. One is for connecting willing living donors with a match for like kidneys, that type of thing. And then I believe they had the high-risk or high match . . . difficult-match registry, and then just a basic person waiting for a transplant registry, but they did not have a willing donor registry that I'm aware of.

Ms. Chartier: — I guess I'm wondering if there might be an . . . Obviously the CBS isn't here right now but knowing how we would feed into that. And I regret and I'm sorry that I didn't ask that this morning, but if we developed a registry, how that would feed into a national registry. Is there any opportunity for us to connect again with CBS? Maybe not coming before us but . . .

The Chair: — We can ask that question. Yes, we can send that question. If you want to formulate it the way you want to ask it and we'll get our folks to help out.

Ms. Chartier: — I'm curious how other provinces feed into that. So you talked about other provinces having, or a few of the other provinces having the registry, but I am wondering how the next steps with CBS, if any of those provinces are tying into that and how that would that work.

Ms. Olson: — Yes, that I'm not exactly sure how they're all tied in with the Canadian Blood Services.

Ms. Chartier: — Yes. No, and I appreciate that. Sorry.

Ms. Olson: — But I mean I find it a little bit odd that every province has got its own system for making their wishes known. And to me it just doesn't make any sense. Or to anybody that I talk to, it just doesn't make any sense. It should just be something that's national. We all do the same thing: we all say yes/no; we all check a box; we all whatever it is that we need to do. But each place is different.

Ms. Chartier: — I think the one thing that I really appreciated this morning about the transplant program coming and presenting — they spoke before the CBS — was talking about the need for culture change where you get to the place, where you do all the work necessary. And they actually aren't supportive of an opt-in. They think that there's lots of other ways to get there. And they spoke about Spain and what Spain had done. But to change that culture . . . well of course I'm going to donate. And that education awareness . . . And sustained, like not just little one-off programs, but continuous education which again someone in your position is well placed to share your story. But you need the support to be able to share it far and wide.

Ms. Olson: — You know, it would be my hope that we could get enough awareness out there that we wouldn't even need a presumed consent program or an opt-out program. That's why I brought up the schools. I know . . . I grew up in Oregon actually, and I know that they have a school program where a recipient and someone else goes in and they talk with the kids. And if you do that every year, you're eventually going to hit, you know, all the kids. Right? And they're just going to become accustomed to it and it's going to be just something that they don't really even think about because it's just, yeah, sure, of course I would, you know.

And if we make it easy for people to make that indication somewhere on forms they fill out or whatever it is, then hopefully it will just become mainstream, and we wouldn't even need presumed consent. But I still think it's a good idea.

Ms. Chartier: — Well thank you very much for sharing your experience.

Ms. Olson: — Thank you.

The Chair: — Mr. Buckingham.

Mr. Buckingham: — Thank you very much for your presentation. You know, for me it was very powerful. And I think it . . . The reason it was so powerful is because it's from personal experience and there's . . . I don't think anything else gives it as much credibility as someone speaking from their own experience. And I guess with that, there is so much information that you presented there. I tried to jot it all down and I got maybe half of it, so would we be able to have your notes after to refer to it.

Ms. Olson: — Absolutely.

Mr. Buckingham: — They're very, very valuable to us.

Ms. Olson: — Okay, absolutely. I do have extra copies here.

Mr. Buckingham: — Okay great. And thank you again very, very, very much.

Ms. Olson: — Thank you.

The Chair: — Well seeing that there's no more questions, I too want to thank you for your presentation. It helps fill in those blanks as well. So we're going to take a brief recess while we get our next presenters ready.

[The committee recessed for a period of time.]

The Chair: — Good afternoon. Welcome back. Before we get started I would like to table HUS 22-28, Cheryl Olson: Submission regarding organ donation inquiry.

Our next presenter is Twyla Harris. I'd like to welcome you to our committee today. Before you begin your presentations if you could introduce yourself and the others that may be presenting with you, and if you are speaking on behalf of an organization please state your position within the organization represented. And if you have a written submission please advise that you'd like to table this submission. Once this occurs your submission will be available to the public. Electronic copies of the tabled submissions will be available on the committee's website.

Once your presentation is completed the committee members may have questions for you. I will direct the questions and recognize each member that is to speak. Members are not permitted to engage witnesses in debate, and witnesses are not permitted to ask any questions of the committee. Our agenda allows for a 30-minute presentation followed by a 15-minute question-and-answer period, and if you would now please proceed with your presentation.

Presenter: Twyla Harris

Ms. Harris: — My name is Twyla Harris. This is my father, Carmen Harris, and my mother, Rosalyn Harris. We would like to begin by thanking you for holding these public hearings on organ donation as we find them very important and something that has been a long time coming.

We would like to take the time today to tell you our family's story and what we are hoping to achieve with an organ donation program within Saskatchewan. We will present ideas such as, but not limited to, an online registry, education, promotions, living organ donations, and an opt-out program.

Mr. Harris: — In 1988, my uncle, Gordon Harris, at the age of 47 was diagnosed with acute leukemia. At the time there was no treatment for this disease. It is now commonly treated with stem cell transplants. My uncle passed away two days before Twyla's third birthday in July at the age of 48. Uncle Gordon — loving, supportive, dedicated to his nephews and nieces — was never married. He had no children of his own. He instead chose to devote his life to caring for his mother and his father, my grandfather Sid Harris, who passed away in '68 of emphysema.

My younger brother Wendell was always tired, cold. He never really had any energy. We thought that he was just lazy, whiny, and so a lot have called him wimpy. Even his nieces and nephews called him Uncle Wimpy. We had no idea that there was something else going on.

In '91 when he was only 20, we found out what was actually happening. He was diagnosed with aplastic anemia after many medical appointments. For those that may be unaware, aplastic anemia is a disease that affects your red blood cells, not allowing them to reproduce normally. Wendell was given two options: blood transfusions which would only work for a short period of time, or a bone marrow transplant. Wendell, along with my parents, decided that bone marrow transplants was the route to go.

All my siblings and I started the process to have blood work done, DNA testing, here in Saskatoon to see if any of us matched. Once all the tests were done, including our children, I was the best match. I travelled with Wendell and our parents to Vancouver in December of '92 as bone marrow transplants were not available at that time in Saskatchewan. While away in Vancouver, my wife Rosalyn stayed at home looking after the children, the three children, as well as the farm.

The bone marrow transplant was a success. Wendell was doing well. He was up walking around, moving. Despite this, Wendell sadly developed an ulcer in his stomach which ruptured. He ended up passing away of internal bleeding in February of '93 while being treated at the Vancouver General Hospital.

Ms. Harris: — My grandfather, Clarence Harris, had spent years working for the RM [rural municipality] of Shellbrook. When he at long last decided to retire it was so that he could enjoy his cabin with his wife, Opal. Grandpa had been sick with pneumonia and he never seemed to be able to lose his cough. He went back to the doctor many times and tried different medications. After multiple tests they found that he had pulmonary fibrosis.

Pulmonary fibrosis is a disease of the lungs, and it tragically has no cure. Grandpa very quickly went on oxygen 24-7. He was told his only option was a double lung transplant. Grandpa and grandma ended up travelling to Edmonton to complete the fit program which was required in order to be placed on the wait-list for lung transplant. After grandpa finished the fit program, they returned home. After only a short time, grandpa got very sick and ended up in Royal University Hospital here in Saskatoon. My grandpa never came home. He passed away on my 19th birthday in July of 2004. My grandpa was 67 when he passed away, but was able to donate his corneas as well as some tissue to help others that were in need.

In 2013 my auntie, Karen Pilon, had gotten bronchitis and it just kept coming back. Her doctors weren't quite sure what was going on. Since none of the medication and treatments were working, they did some testing and realized that Auntie Karen had the same disease as her father Clarence: pulmonary fibrosis.

Auntie's illness progressed very quickly. She too was on 24-7 oxygen and in need of a double lung transplant. In February of 2014, she ended up in ICU at Royal University Hospital. Auntie was not going to get better. They decided to send her to Edmonton with the hope to give her a better chance for a transplant. In order to send her and keep her alive, they needed to put her on an ECMO [extracorporeal membrane oxygenation] machine. Once she was in Edmonton, they kept her on the ECMO machine and sedated her. She stayed like that until it was decided that even if she received a transplant, she would not survive.

On March 25th of that same year, my uncle Clarence made the difficult decision to take his wife off life support so she herself could become a donor. Auntie Karen was able to donate her liver, kidneys, and pancreas. Auntie Karen saved four lives that day.

Following auntie's death her husband Clarence, with both the Harris and Pilon families, started the Karen Pilon Organ Donor Awareness Foundation. Through this project Clarence has been able to help raise funds and help support other families who are going through similar things.

Along with fundraising, with raising funds, the foundation has also spent many hours creating ways to promote organ donation. One particularly successful promotion was billboards across Prince Albert displaying stories of individuals who either received, donated, or passed while waiting for the organs they needed. Clarence and the family have also attended events like Transplant Trot, local parades, Prince Albert SPCA [Society for the Prevention of Cruelty to Animals] golf tournament, and Shoot for the Vitals. Recently we've started selling T-shirts, green bracelets, and stickers.

This year the Prince Albert Exhibition Finished 4H Beef Show and Sale chose the Karen Pilon Organ Donor Awareness Foundation as their charity of choice, allowing the foundation to receive the funds from the sale of the charity steer. The charity steer this year was supplied by the Wild Rose 4H Beef club. This is the club that auntie's children and all of her nieces and nephews have been a part of for over 22 years. The charity steer was cared for and trained by my own family on our farm. The charity steer ended up bringing in $27,150. This money was put towards purchasing an ECMO machine for the University Hospital in Edmonton. This is the machine that kept my auntie alive which helped get her safely to Edmonton.

The summer after my auntie passed, my brother Tyler Harris had an idea for a fundraiser. Tyler, along with my Uncle Ralph Harris, came up with the plan for Shoot for the Vitals. Shoot for the Vitals started in July 2014 and began as a skeet and 3-D archery shooting competition. The Harris family has now successfully held this event for three years in a row on our family farm near Prince Albert. This year we decided to only have the 3-D archery shoot. Over the three years, we have been able to financially support several individuals from the

Shellbrook and Prince Albert area as well as the Karen Pilon Organ Donor Awareness Foundation. Our number of participants has risen every year and continues to grow.

By doing this our family has been able to financially help a very close family friend, Rick Galloway. Rick was diagnosed with a lung disease as the same time as my auntie and also required a double lung transplant. Rick was lucky enough to receive his lungs in July of 2014, but sadly his kidneys started to fail and would require a kidney transplant. Rick passed away last year in August of 2015.

Mr. Harris: — This March my brother Ralph Harris was also diagnosed with pulmonary fibrosis. He is currently undergoing doctors' care in Saskatoon, doing CT [computerized tomography] scans, blood work, chest X-rays, breathing tests every three months to see how fast the disease is advancing. But we all know a lung transplant is the only option. He is currently waiting to start his fit program and be placed in a transplant list.

Ms. Harris: — As you can see, organ donation is a huge part of our lives. It has affected us in many ways. While all of this has been happening, we have found out that the cause for our family having these many issues is that we are carriers of a genetic factor disease called dyskeratosis congenita or DKC. DKC is a disease of the bone marrow that affects your breathing system, showing that aplastic anemia and pulmonary fibrosis are all linked.

[14:15]

Now that you've heard our story, we would like to explain to you what we would like to see happen within Saskatchewan in order to increase organ donation. The first thing we propose is the creation of an online registry for organ donors. This online registry would be created and maintained by the provincial government. It would be developed for use in all Saskatchewan hospitals. This registry would take the legal and decision-making burden off of the family, at least to some extent. It would work alongside the signed card and sticker on the health card. With this we asked the provincial government to also push the federal government to adopt and put into law Bill C-223, *Canadian Organ Donor Registry Act*.

In conjunction with the stand up of a registry, the public would require an awareness campaign on considerations for folks to speak with their families about their wishes, to describe the types of organs and tissues that can be donated, and the types of living organ donations that are possible. We would like to see the creation of this online registry to follow the registries already in operation in Ontario, British Columbia, and Alberta.

Next, we would like organ donation to be added to the grade 8 health or science curriculum. Topics of instruction would be options of donation, myths and facts, and the different systems across Canada and the world. This would allow for organ donation to be considered at an earlier age and permit youth to have the discussion with their families. Speaking with many youth, most are unaware of organ donation and surrounding considerations. Education at a younger age will help with the discussion and help raise numbers of organ donors.

The province of Saskatchewan currently has a promotion happening now called, Offer Hope. I personally do not feel that this is in any way effective. As a family that is heavily involved with promoting organ donation, we have hardly seen a commercial or a poster anywhere. I have repeatedly spoken with co-workers and friends about the Offer Hope campaign, and none have been aware of it.

In order to fully educate the public and to increase the number of organ donations, the reach and focus of the advertising campaign needs to be broader. The advertising needs to promote organ donation by teaching facts and sharing information. Stories are important but must associate the facts and a call to action. There needs to be an ask coming from an awareness campaign which ties in with the online registry. The promotions need to be shared on all platforms, social media, print, television, and radio.

We see a generally expanded purpose for the Saskatchewan Transplant Program. They should be attending events and promoting organ donations more widely. It would be great to have them attending events that can be about raising awareness on organ donation as well as public events like Broadway Street Fair, Regina Mosaic, and different exhibitions.

I recently decided to look into living organ donation, and the process is frustrating and takes an extended period of time. Even seeking out information required me speaking to four different organizations, which still did not yield the information I needed. This process needs to be easier both to obtain and to start the process. A web page that has a clear outline of the process and who to contact would be exceptionally helpful.

I also reached out to my insurance provider to find out what coverage I could get if I chose to do this. I found out that I would only get short-term disability. I would not receive coverage of travel and treatment. If I was required to travel to Edmonton, my travel, meals, and hospital room would not be covered under my benefits. This puts a large roadblock up for anyone who would like to do living organ donation.

Increasing information and promotions would help to increase the number of transplants for those who require kidney and liver transplants, which will in turn lower the number of individuals who will require dialysis and other treatments.

Finally, while all of the above is happening, we would like the provincial government to start public consultations to move the province to an opt-out program. This is presumed consent unless the individual has declared their intention to not donate their organs. Additionally, the current barriers to gay men being able to donate their organs, tissue and blood needs to be changed and removed as these barriers are not based on actual science but on a behavioural practice. They are discriminatory in nature.

By implementing opt-out and removing the barrier set against gay men, we can increase the number of organ donors available. This will help reduce the number of trips to Alberta for treatments and testing. With over 80 per cent of Canadian population saying they would donate their organs, this is an idea that would be overwhelmingly supported by the majority of the population. This would make Saskatchewan leaders in organ donation in North America.

Thank you for allowing us to present our views and story to you. We hope that you will take this into consideration, and we are willing to continue to work on major improvements to our organ donation system.

The Chair: — Well thank you very much. We'll start questions with Mr. Buckingham.

Mr. Buckingham: — Well thank you. I had no idea when I sat down here that I knew you folks. These people are from Shellbrook and went to school with Rosalyn and played hockey against Carmen. So always nice to have a connection.

But you know, the last presenter, I asked them if I could have their notes just because there's a lot of information in there that's really hard for us to get down on here. I'd love to have your notes if I could.

But I really want to reach out and thank you for sharing with us. You know, you took a lot of time to put that together and share it with us and, you know, that's not always easy. And so I really appreciate what you're doing, and it's an important topic to us. So thank you very much for your submissions.

The Chair: — Mr. Docherty.

Mr. Docherty: — Thank you, Mr. Chair. Thanks so much for attending, and it was a very valuable presentation. I particularly like the fact that you came with some suggestions and some solutions. That's very valuable.

I'm interested in a couple of things. One was the science curriculum piece where you wanted that to be included. And did you put any more thought into what that might look like and in which part of the curriculum it would fall? And also, because I'm 100 years old apparently, I couldn't read your opt-out pieces. There was two options of yes, and I couldn't read the second one. But you had two yes options, and you had a no.

Ms. Harris: — Oh, the pink one?

Mr. Docherty: — That's right. Yes, so I want to be an organ donor. I think it says . . .

Ms. Harris: — Opt-in.

Mr. Docherty: — Right.

Ms. Harris: — And then it says choose to register as an organ donor.

Mr. Docherty: — Okay.

Ms. Harris: — And then the other one says, do nothing; you have no objection to becoming an organ donor. And then it's, I don't want to be an organ donor. Then you'd opt out. So that's what our current system is.

Mr. Docherty: — Okay. Okay thanks for that. So yes, if you could maybe talk about your thoughts in regards to the science curriculum.

Ms. Harris: — So the idea behind the science curriculum is . . . I actually work with the cadet program as well. I'm an officer and I've worked in it for nine years now. So this is something I specifically teach. We have a period that we can kind of teach about anything we choose. I always choose this.

And speaking with them, lots of them are around that grade 8 level, and they've never heard . . . they don't know anything about it. They might have seen it on a TV show; they don't know anything about it. So the basis of it would be to introduce this idea of organ donation to them and clarify any myths that they might have heard and correct them so that they have a full understanding of what it is. It also then causes them to go home and then talk to their families: oh, I learned about this today. What are your thoughts?

Mr. Docherty: — Yes, if I could just have one quick follow-up. Yes, that's very helpful. I might have the answer in regards to my question as soon as I ask it, but in terms of the age of opting in or opting out, right now we'd obviously be dealing with driver's licences. But do you have any thoughts in regards to that in relation to parental consent and all those other pieces?

Ms. Harris: — My thought process is on that is, it would follow along the age of majority. So if 18 is now when you can make the decision of whether or not you'll donate your organs or not, then they would stay that way. It would just be that the discussion would just start sooner instead of waiting till they're 18.

Mr. Docherty: — Thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you, Harris family, for your time here today and sharing a little bit about your story, or multiple stories actually. The one piece that I'm . . . Well it's all very important, but that piece around the pre-op period, you talked about being a living donor and how difficult that might be. Not all of us have a lot of spare money. We've heard from folks who are in fact waiting for donations, and that six-week pre-op period for the lung transplant is hard on people, and then the recovery period. Do you have any thoughts on how better to support people through that?

Ms. Harris: — Well when it would come to living organ donation, I think something needs to be put into legislation, into health, within an insurance kind of area, saying we will cover somebody who is willing to go through this process. So whether it be like 70 per cent of their income would be covered, obviously not the full. It's like maternity leave; you don't get your full amount, but something that would offset the expenses. As well as if you are travelling to Edmonton, hospital rooms aren't cheap, and you're obviously probably not going to also get a loan. So if you have a spouse or a family member who's going to travel with you, their living costs also cost. So it would be kind of covering all of those factors to just take that burden off of that person to make it easier for them to do it.

Ms. Chartier: — Well thank you. I really appreciate your comments around that education piece, and we've heard that in educating young people. And you talk about culture change; we've heard lots about culture change in our presentations so far. And I think that that's a good place to . . . There's many places in which one can work on culture change, but that makes a lot of sense in school where our kids are a captive audience. So thank you for that suggestion.

Mr. Harris: — [Inaudible] . . . my thought on the age limit. I think anything under 18 with the signature of a parent because we have so many children that are any age that are looking for transplants of some type. And not all transplant organs fit into certain people's bodies; there's different size categories. You know, I'll use lungs for example. Lungs are only fit in certain size cavities. We can be at the same height. We can be the same weight, but if those cavities are not the same size, it isn't going to work.

So I think it should go back to any age, whether you're 4 years old or you're 16 years old. If the parents have signature on it, then I opt in, you know, and I sign for it. I'm the legal guardian. And that way there we're covering all ages. We're not just covering adults because that's what I see a lot happening in our process what we're doing right now when we're doing organ transplants. It's always in the adult. We don't cover the young, the youth. We don't cover them, and we need to.

The Chair: — Ms. Carr.

Ms. Carr: — Yes, that's an interesting comment that you make because if we were to go down the road of presumed consent everybody would be included. Then as a parent if you have underage children and you feel like this isn't the choice you want for them, then you can opt out. And we had a presenter earlier say to us if you really don't want to be a part of a program like this, you will take the time to opt out.

Mr. Harris: — That's exactly right.

Ms. Carr: — Yes. Thank you.

The Chair: — Seeing no other questions, do you wish to table your presentation?

Ms. Harris: — Yes, I can.

The Chair: — So we'll call this HUS 23-28, Twyla Harris: Submission regarding organ donation inquiry. Thank you very much for your time today. You've put a lot of thought into this and a lot of work. So thank you.

So we'll take a short recess, and we will resume at 2:45.

[The committee recessed for a period of time.]

[14:45]

The Chair: — Welcome back this afternoon, committee members. Our next presentation is by the Lung Association of Saskatchewan. I'd like to welcome you to the committee today. Before you begin your presentation, could I have each of you introduce yourself, and if you're speaking on behalf of your organization, could you state your position within the organization represented. If you have a written submission, please advise that you'd like to table a submission. Once this occurs, your submission will be available to the public. Electronic copies of the tabled submissions will be available on the committee's website.

Once your presentation is completed, the committee members may have questions for you. I will direct the questions and recognize each member that is to speak. Members are not permitted to engage witnesses in any debate, and witnesses are not permitted to ask questions of the committee.

Our agenda allows for a 30-minute presentation followed by a 15-minute question-and-answer period. And if you would now please proceed with your presentation, that would be great.

Presenter: The Lung Association of Saskatchewan

Ms. Hubick: — Hi, my name is Jill Hubick. I'm a registered nurse and certified respiratory educator with the Lung Association of Saskatchewan.

Ms. Nelson: — I'm Nicole Nelson. I am a double lung recipient.

Ms. L'Oste-Brown: — I'm Charlotte L'Oste-Brown, waiting for a double lung transplant.

Ms. Hubick: — So thank you all so much for the opportunity for us to provide a written submission as well as present to you today as to how the Government of Saskatchewan can increase the rate of organ donation and improve the effectiveness of the organ and tissue donation program in Saskatchewan.

For the people in our province suffering from severe lung disease, having a lung transplant may be their last and only option to survive. Lung transplant surgeries are considered when a severe lung condition is continuing to progress and when all other available treatments and medications are no longer helping, the individual's life expectancy is in the range of one to two years without the lung transplant, and the procedure could result in better quality of life.

Lung diseases affect one in five Canadians, and several of those lung diseases may lead to the need for a lung transplant. In fact every 15 minutes someone dies of lung disease in our country. The most common lung diseases for which a lung transplant is often required includes pulmonary fibrosis; chronic obstructive pulmonary disease or COPD, which also includes chronic bronchitis as well as emphysema; and cystic fibrosis. Advances in treatment have made lung transplant possible for a greater number of patients; however, the demand and the wait-list for donor organs is growing at a much faster rate then the current organ donation rates.

Unfortunately diseases like COPD are also on the rise; one Canadian dies every hour from COPD. This disease is currently the fourth leading cause of death in both men and women in our country, and it is soon to be the third. COPD is also the leading cause of hospitalization among seniors in our province.

From 2005 to 2014, the number of patients on the waiting list and the number of lung transplants performed steadily increased by 52 per cent. In 2014, 226 lung transplants were performed in our country, but 300 people remained on the wait-list and 70 people died while waiting for a transplant. In 2015 for

Saskatchewan residents, four Saskatchewan residents had lung transplants and 10 remained on the wait-list. The need for more organ transplantations will only increase in the future as our population ages.

The other two most common reasons for a lung transplant to be performed are for those with pulmonary fibrosis or cystic fibrosis. The unfortunate reality is that many of these patients will die waiting for a lung transplant.

Those with cystic fibrosis often die quite young. Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. It is an inherited disease that causes abnormally thick and sticky mucus that is produced in the lungs. The mucus blocks the airways in the lungs and the lungs become infected easily with bacteria. This can lead to life-threatening lung infections and progressive and severe lung disease.

Pulmonary fibrosis is a disease when the lungs lose their ability to transfer oxygen to the blood stream, causing shortness of breath, and the vital organs are deprived from the necessary oxygen to survive. The causes in many cases are idiopathic or unknown. In some, risk factors such as environmental exposure, genetics, connective tissue diseases, certain medications, and smoking may be identified. In many cases pulmonary fibrosis is a fatal condition with no cure, and no available alternative treatment has been shown to prolong survival other than lung transplantation. The disease course is often rapid with distressing symptoms of shortness of breath and cough. Sadly among patients with idiopathic pulmonary fibrosis, 50 per cent of those patients will die within two to three years of their diagnosis.

The number of transplants done each year depends entirely upon the number of donor lungs that become available and the systems in place to support these procedures and patients. Canada's donation rates are less than half of the best-performing countries and has plateaued over the last decade. Within Canada, Saskatchewan has the lowest donation rates. An average of four patients in Saskatchewan receive a lung transplant each year, which represents approximately a third to one-half of the patients in the province who are actively listed. Although medical care pre- and post-transplant is done in Saskatchewan, no lung transplant surgeries are done here, and all patients needing this life-saving procedure must travel out of the province.

The process of being listed for and receiving a lung transplant is fraught with enormous stress, certainly for the patient and their loved ones. Patients ask themselves, will they survive long enough in order to receive a transplant? Will an appropriate donor even become available? Can I along with my family afford the cost of travel, medication, and time away from work? The costs are not only financial, but emotional and psychological.

Should someone be fortunate enough to receive a transplant, the process can be expensive. Although the cost of surgery itself is covered, there are many other costs to consider. There are currently only five hospitals in all of Canada that perform lung transplants. There are no centres located in Saskatchewan, forcing all of our province's transplant recipients and donors to go out of the province, typically to the University of Alberta Hospital in Edmonton.

Costs for travel, accommodation, and food for the patient along with their support person must all be considered. Presently through charitable organizations such as the Kinsmen Foundation and Telemiracle, travel, accommodations, and food may be covered for the transplant recipient. There are also costs for support people, a mandatory requirement.

The core immunosuppressant medication post-transplants are covered, but there is a gap in coverage for medications needed to treat the side effects from the anti-rejection drugs, medical monitoring equipment, the cost of ongoing bills at home such as mortgage and utilities, loss in salary for both organ recipient and their support person while accompanying the patient undergoing the transplant. Child care is to be considered, kennel costs for pets, etc.

Those who receive a transplant, along with their support person, are required to live near the transplant centre in Edmonton for a week-long assessment phase, a four- to six-week pre-transplant physiotherapy program, and a minimum of three months post-surgery. During the first year of post-transplant, the majority of the medical care is done in Edmonton, with frequent trips between home and there.

The Lung Association's vision is healthy lungs for everyone. Organ donation certainly helps us strive towards this. In order to increase organ and tissue donation rates and improve upon Saskatchewan's existing program, it is essential for us to gain perspectives from the patients themselves.

Ms. Nelson: — I was told I had pulmonary fibrosis at just 18 years old. With a long-standing family history, I've lost 16 of my family members. It was because of this that I went in to get tested and I was diagnosed with only a few symptoms.

However, in 2013 I noticed a rapid decline. In February of that year, I caught a cold and I couldn't get over it. I had a dry cough, shortness of breath, and I found myself avoiding stairs, parking close to doors because walking far distances and activities that once seemed effortless were leaving me breathless. Later that year, I was admitted into the hospital and put on oxygen. It was then that I was referred to the Saskatchewan transplant clinic. The process involved multiple appointments and tests such as bloodwork, pulmonary function tests, bone density tests, CT scans, chest X-rays, echoes, and ECGs [electrocardiogram], just to name a few.

In January 2014, I met the criteria to join the pre-transplant program in the University of Alberta. So I had to move to Edmonton. I attended a six week pre-transplant physiotherapy program, which required myself and a support person to move. Unfortunately due to financial reasons, I along with my family could not afford to do this. In order to have another chance, I was forced to go to Edmonton on my own and every weekend with a different support person; whether it was my husband, my in-laws, a friend or a family member, they came to see me, to help me with my assessments.

I had to go to physiotherapy, occupational therapy, and educational classes to learn about my upcoming transplant. The hospital and clinic were a far distance apart, and my lack of endurance and breath made this very challenging. I relied heavily on my friends and family to push me in a wheelchair in order to get to my many appointments.

After my six-week program ended in Edmonton, I returned home to Saskatoon to await the call. During that time I carried a cellphone with me everywhere I went. I did the best I could to stay active and strong for the possibility of upcoming surgery. I managed to stay positive by spending time with friends and family and also doing my best to promote and explain the importance of organ and tissue donation.

Finally in July of 2014 I received my life-saving call. My husband and I took an air ambulance to Edmonton where we both remained for another three months in order to recover from my transplant. We applied for assistance from Telemiracle and were able to stay in a condo that had reduced fees for transplant patients through the GoodHearts program in Edmonton. My husband also applied for compassionate care, which gave us limited funds. Today I describe receiving my transplant as very humbling but an expensive process.

I believe that the best way to increase the rate of organ donation is to increase the province's awareness about the importance of organ donation. In Saskatchewan, having one's family advocate for us is vital. Everyone should have conversations with their families because ultimately the families are the ones making those life-saving decisions. It is my hope that organ and tissue donation will become a normal conversation among all families and those wanting to donate. They need to have their intentions met.

I also want to see greater efforts among the health care system to make sure and ensure that the health care providers are ready to respond to all opportunities for donation and to make the most of every suitable organ. Thank you so much for allowing me to share my story with you today.

Ms. L'Oste-Brown: — I'm Charlotte L'Oste-Brown. I have always led an active, busy life. I'm a mother of two. I've coached softball, sat on local school boards, all while owning and operating a 15,000 square-foot greenhouse and working with a mixed farming operation in my hometown of Hazenmore, Saskatchewan.

In 2003 I was diagnosed with the terminal disease of pulmonary fibrosis. I gradually stopped doing any physical things like cutting grass, lifting objects, performing quick movements, enjoyable hobbies such as curling or dancing. I did give up my greenhouse business right away, immediately. As my disease progressed I had also to give up the two-storey home along with my greenhouse. I now live in a room-and-board situation closer to medical services in Regina.

[15:00]

In the summer of 2014, my oxygen saturation dropped to 38 per cent from a normal 98 because of an infection and the thick smoke around Regina from the forest fires at the time. My condition was serious and I was hospitalized. I was put through rigorous testing to determine if a lung transplant would be possible, and later I was sent to Edmonton for my six week pre-op physiotherapy program. I have now been listed for a transplant list since December 1st, 2015, which I've been told by my Edmonton doctors I am at the top of the list.

I have to take immune suppressants for my illness while I wait for my lifesaving call. Each day I live with caution because my greatest enemy other than pulmonary fibrosis itself is infection. I describe the past few years as daunting, frustrating, and very stressful. I'm attached to a 50 foot hose in my room, in my home, and it gets tangled continuously. And I have to go everywhere with oxygen. I go to bed every night hoping I will make it through the night without choking, and then I start each day wondering if today is the day to get my second chance. I often feel that I've been sent actually home from Edmonton to think simply about coping with death.

To keep moving forward, I rely on my support system. I have also embraced an advocate role in actively seeking opportunities to educate and inform the public about organ and tissue donations by sharing my story. I believe my story will have an impact, because I'm not a pamphlet in the mail. I am a real person. I am a real person, not waiting for someone to die, but rather a woman who has no other choice but to wait for someone that has made that choice to give the gift of life.

I encourage everybody to talk to their family about their wishes, to become an organ donor today. Because waiting for tomorrow may not happen for a lot of us waiting. And I thank you again for listening to my story.

Ms. Hubick: — 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. Stronger public education and awareness campaigns are required to ensure more Saskatchewan residents not only speak to their families about their wishes to be an organ and tissue donor, but that their commitments to be one are carried out.

Our first recommendation is that funds be allocated towards robust organ and tissue donation campaign that debunks common myths and focuses on the essential need for all Saskatchewan residents to warrant that their intention regarding organ and tissue donations are met. It is our goal that becoming an organ and tissue donor is no longer a rare occurrence, but rather a norm Saskatchewan residents are accustomed to. This will not only save more lives, but absolve loved ones from making such an important decision themselves when an immediate response is required during such a distressing time.

Secondly, we propose that the government ensure that the system is ready to respond to all donation opportunities and guarantee that the most is made out of every donor organ by allocating necessary resources and appropriate management to understand and explore medical and logistical reasons why donors or potential donors are missed in our province.

Third, we recommend funds be allocated to train and empower physicians, surgeons, and other health care practitioners to do their part in identifying and referring potential donors, allowing a complete culture shift within a patient-focused care system to ensure every member of the treatment team is aware which patients may qualify to be an organ and tissue donor. Funds should be allocated specifically to support medical management of potential organ donors. Accessibility of essential services for recipients and their support systems are also imperative.

We further recommend the government make certain adequate and affordable housing accommodations are available closer to treatment centres regardless of the patient's socio-economic status, and that funding is also safeguarded to support both the transplant recipient and their required support person for the additional costs they incur such as support for continuous everyday cost of living in Saskatchewan including utility bills, mortgages, child care, pet kennels, out of province, and absent from the work force.

Thank you so much for the opportunity and for considering our recommendations.

The Chair: — Thank you very much for your presentation. We'll open the floor for questions. Mr. Docherty.

Mr. Docherty: — Thank you, Mr. Chair. I thank you so much for your presentation, but also for sharing and such personal details. It must have been hard for you to do that, but we're appreciative of the fact that it's very helpful for us to hear these stories. And again thank you for making the effort because I know that it would be probably be fairly difficult to get here. So thank you for that.

I'm interested in . . . you talked about allocation of money availability in terms of debunking myths. So have you thought about what that might look like in terms of the debunking of the myths and how we would go about — obviously it's an educational piece — how we'd go about doing that? Which part? Is it education? Is it schools? Is it media? What are your thoughts?

Ms. Hubick: — I think in order to really get the message across — and we recommend a robust campaign, or a robust strategy — I think we need to start at the education level. But also look at media, look at as many outlets as possible. Look at some of the common myths that are out there with organ donation, some of the fears that are out there. Whether that be, you know, a concern if you are an organ donor or that you've said that you would want to be, that you wouldn't get the same treatment at the end-of-life stage. That is a common myth.

As well as looking at, you know, people think that if they have the sticker on their health card, that's enough. It's not a common conversation that happens among families. As well as, there's quite a lot of details that go with organ donations. You know, people can be very specific as to which organs they would be comfortable with, or organ and tissue. As well as some of the myths about who can receive one. It's not as straightforward as people would often think.

So getting people talking about it, starting at the education level for sure, but robust campaigns and media. And all media in today's age would be appropriate, we feel.

Mr. Docherty: — Great. Yes, thank you for that. I appreciate that.

The Chair: — Mr. Buckingham.

Mr. Buckingham: — Well thank you very much for your submission. I really appreciate it. I was just wondering about, you had said after your surgery it took about three months that you spent in Edmonton. Is that pretty . . . or is that accurate? Is the way I heard it right?

Ms. Nelson: — Standard is three months after surgery. It can be longer, depending if there are complications. It's usually three months out of hospital. Once you're out of ICU and off the transplant ward, they do a recovery period with you.

Mr. Buckingham: — Okay. So that's a typical time frame that you would need. And so during that three months, you would have someone else with you at that time too, to help you?

Ms. Nelson: — Yes. The entire three months you are required to have a support person with you. It is part of the recovery process just basically because you can't do too much. You need somebody to help cook and clean, transportation. Just to have somebody there for support as well, so you're not alone. It's quite the process.

Mr. Buckingham: — Okay. And did I hear at the start, were you submitting your notes at the end?

Ms. Hubick: — I'm sorry. Yes, I have a written submission that was emailed electronically, and then I provided some paper copies as well for today, if you guys need.

Mr. Buckingham: — Great. Thank you, that's all I have.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you very much for your presentation and your stories. They bring this whole issue to life. One of the questions, or the piece that I'm interested in is both that pre-op and post-op period and the ability of patients to be able to pay. And you addressed that in some of your recommendations, but I'm wondering . . . So you in your pre-op period, you're supposed to have a support person with you and then you ended up just being able to, because of financial barriers, just someone with you on the weekends or when that was possible?

Ms. Nelson: — Yes. For the most part, when I did my six-week program, on Mondays was a busy day. I met with the transplant team doctors. I had physiotherapy, occupational therapy, and then there was usually a class to teach you about organ transplantation, what to expect with surgery or after. And so those fell on Mondays, were my busiest days of the week. And so that's when I had a support person come so they could push me around in a wheelchair.

The rest of the week, I fended for myself because it usually was just physiotherapy and classes.

Ms. Chartier: — Yes. That sounded like it was difficult, nonetheless, on your own. I think my question . . . Obviously a double-lung transplant is life-saving and it is a gift, but are there ever occasions . . . Because of financial barriers, have you come across people who can't do it? Obviously charity fills the void sometimes, but I guess in some situations it wouldn't. Are there ever occasions where people turn down or can't have the transplant because they can't afford the time away, like the pre-op period, or they don't have a support person that can afford to be away.

Ms. Hubick: — I know that it's a factor when people are deciding for a lung transplant. Charities will assist but it is a big concern and many will make drastic changes in their life. It does come into play with the decision of whether they decide to in turn go forward and take the lung transplant themselves. That definitely weighs, is a deciding factor for many patients.

Ms. Chartier: — Yes. Do you know of people who have decided not to go that route because of finances?

Ms. Hubick: — You know, personally as a nurse with the Lung Association, that might be a better question for Dr. Fenton who's presenting behind us, one of the respirologists who sees a lot more patients specific to lung transplantation. We certainly get the calls of people asking if there's any way that our organization can assist them because they're struggling financially. And I know our organization will step in and help with some of the equipment and that sort of thing, as well look at people on a case-by-case situation. So that's usually the calls that we get is they've decided to move forward and have a transplant, but they're struggling financially and want to look at all the options that are available to them. I hope that answers your question.

Ms. Chartier: — It sure does. Thank you very much.

The Chair: — Ms. Rancourt.

Ms. Rancourt: — Thank you for your presentation. Actually I don't know who would be best to answer this question, but it's regarding something that you said at your last presentation, Charlotte, in Regina. I remember you saying that when patients get to this point of feeling very desperate and they're feeling like they're losing a lot of hope, that suicide sometimes might become an option. And I don't know if there's any documentation or anything that talks about suicide rates for maybe patients waiting for transplants. So I don't know if you guys have more information with regards to that or not.

Ms. L'Oste-Brown: — I made that comment because I was aware of some people that suicide was definitely a thought process, and in doing some of the reading where, you know, from sites that it has happened. I have no other access to that other than information, exact stats regarding that. But the mental anguish, I can tell you that it is terrible. And I have heard people say that they would be ready, you know, to end it all rather than to go through the wait. It's very excruciating and every individual is different. There again that would be a question I would certainly ask. Dr. Fenton might be better to answer on the stature of that as well, or perhaps Jill does.

Ms. Hubick: — I'm unfortunately not familiar with those statistics, but I can look into it and submit that to you if I find anything, if you like.

Ms. Rancourt: — That would be really great. Thank you.

The Chair: — Seeing no other questions, I'd like to table HUS 24-28, the Lung Association of Saskatchewan: Submission regarding organ donation inquiry. Again thank you for your presentation and we'll take a brief recess while we get ready for our next presentation. Thank you very much.

[15:15]

[The committee recessed for a period of time.]

The Chair: — Good afternoon. Welcome back. Our next presenter is Mr. Mark Fenton. I'd like to welcome you to the committee today. Before you begin your presentation, if you — I see you're alone, so I'm going to skip this next line — if you could just introduce yourself for Hansard. If you're speaking on behalf of an organization, state your position within the organization represented. And if you have a submission, please advise that you'd like to table the submission. Once this occurs, your submission will be available to the public, and electronic copies of the tabled submissions will be available on the committee's website.

Once your presentation is completed, the committee members may have questions for you. I will direct the questions and recognize each member that is to speak. Members are not permitted to engage witnesses in any debate, and witnesses are not permitted to ask any questions of the committee. Our agenda allows for a 30-minute presentation and a 15-minute question-and-answer period. And, sir, if you'd please proceed with your presentation.

Presenter: Mark Fenton

Mr. Fenton: — So I'm Mark Fenton. I'm a transplant respirologist here in Saskatoon. I have an appointment at the University of Saskatchewan. I'm the director of the lung transplant clinic; in fact I founded that clinic here in Saskatchewan back in 2008. I'm the medical director for the sleep disorder centre here in Saskatoon, and I'm the program director for our training program at the University of Saskatchewan.

So I'm going to start with this. Lung transplantation is a life-saving procedure. I think you've gathered that from the people that came before me, but I really want to emphasize that to you that this is a life-saving procedure for patients with respiratory failure, end-stage lung disease. And the thing you need to be reminded, I suppose, about that is that we don't have a lot of things to support these people, like a dialysis machine for example. And I'm not criticizing kidney here at all, but I'm just making the comparison that I don't have a dialysis machine that I can use to bridge these people along. So this is like we are entirely dependent on deceased donors for this. And so organ donation is part and parcel of my everyday life. I'm not an organ donation specialist; I'm someone that specializes in the management of the person that is receiving that organ.

[15:30]

So just a little bit about me. I was born and raised here in Saskatoon. I'm a graduate of our University of Saskatchewan. A lot of my training was done here, and I did a clinical fellowship in transplantation at the University of Alberta. So what I do is I see patients with end-stage lung disease, as I mentioned, and go through the process with them of deciding is transplant an appropriate thing for them. Is it time? Then I make arrangements for them to be worked up and listed for transplant.

Transplantation occurs outside the province, which you heard. We'll talk a little bit more about that. And once the transplant has occurred, the transition of care, you know, that three months you were asking about, if everything goes like clockwork it's three months. If there are complications, it gets stretched out. But sometime shortly after that, I start to take on the management of these patients in collaboration with my colleagues, in the end, you know, trying to get some insight into that.

So as I mentioned, I established a clinic here in Saskatchewan, first of its kind, in 2008. Prior to that everybody went out of province for all of their care, routine care. It's a multi-disciplinary clinic, so it's not just myself. There are two transplant coordinators who are nurses, a pharmacist, a social worker who comes. And recently I've managed to attract another physician to participate in the clinic, which is very helpful to me. But this is a partnership. So the University of Alberta is the hub, and I'm one of the spokes, okay? So the University of Manitoba has joined us, the University of Calgary, and we represent a pretty wide geographic area. So this is the area that we take care of; it's arguably the largest geographic lung transplant program in the world, not the largest by numbers, but just by geography. That presents some challenges.

So just to give you an idea of sort of where we're at, since I started I've had 214 people referred to me for transplant consideration. Seventy-one of those people have gone on to be listed for transplant. Unfortunately not all of them have received a transplant. And one of the hardest parts of that conversation is to explain to someone who's facing death there's a real possibility a donor won't come along for you. And there's a variety of reasons why that might occur, but one of the most important is the lack of donors being available.

And it's a challenging thing to try and help people understand because we live in a province that gives. You know, Telemiracle has been alive since — what? — 1977. Five, six million dollars a year every . . . Like we give, but that has not translated into this domain. And I think that that's just not because people aren't willing. I think it's that the processes involved and the understandings of the public, I think there's some disconnects there that we can fix. And I'll get into that.

But anyway, we've had 45 post-transplant patients. Some of the patients that are followed in my clinic were transplanted elsewhere because some of them have been around for a while, even preceding transplantation in the West, so for example done in Ontario where lung transplant was pioneered.

At the moment there's . . . Actually these numbers are out of date. I just made this, but we now have nine people on the active list as of this morning; seven on the status zero list who are inactive but almost there. So this just is a snapshot. And this, I haven't updated this for a while. Each of those red dots represents a community in Saskatchewan that has a lung transplant in it, or maybe several. And you know, the geography of our province is an important consideration in all of this, and we'll talk about that.

We enjoy very good post-transplant outcomes in our program. So you can look at our five-year survival as kind of the benchmark we use internationally to measure transplant outcomes. So internationally, five-year survival is rated around 53 per cent; ours is approaching 80. So we enjoy good outcomes in Western Canada, and part of that is because of the collaborative nature and volume of the program.

But unfortunately demand remains higher than supply, you know, and it's the whole reason we're here. I don't think I have to educate you on that particular notion, you know. But the demand is growing. I've had 32 referrals this year alone so far. It's only September. And unfortunately, people die on the wait-list. So our wait-list death rate is in the neighbourhood of 20 per cent, and that's for the most part just because we don't get enough donors through that are appropriate to our patient population. That's not unique to Saskatchewan or Western Canada. The whole country struggles with this.

This is from that report from Canadian Blood Services that came out on Friday. You probably saw some of this earlier today. I heard that CBS was here making a presentation. This is just a different way to think of it. You know, in the top right there is, you know, the statistics for lungs. And 70 people — this is the most recent CIHI data — 70 people died waiting for a transplant in 2014. And you know, that doesn't need to happen. I think we can get to a point where that doesn't happen, but it's going to take a lot of energy, a lot of investment, and some creative thinking.

So ours is the lowest donation rate in the country, and we need to change that. And I have some ideas for you as to how to do that. So it's not that we don't have the population to have lots of donors. This is something that I just got off the Stats Canada website. So the circle represents the number of deaths between, I think it was July 1st, 2014 to June 30th, 2015. So that's 9,798 people died. So two-thirds of those people would've died in hospital on average. That's the usual. So that takes us down to about 6,500, and about 1.4 per cent of those patients would be, you know, potential donors. So that's 91 potential donors in Saskatchewan as opposed to the 10, roughly 10, that materialized during that time frame. So I think there's the opportunity here to try and realize those other 80 people.

So where does it break down? Well you've heard probably multiple times today the stickers on the health card, although a great idea to signal I support organ donation, maybe isn't the best tool to operationalize the person that wants to be an organ donor into an organ donor because it doesn't carry any weight. The next of kin can override that. They may or may not have their card with them when they die. So you know, I think that it's a good idea, but it's lacking in sort of the ability to follow through on it.

Public awareness I think is an issue. 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 and, you know, it's a real skill for people to talk to a family in that situation. But those people, I think we as a community need to talk about it more so they're not in that situation, so that they know what their loved one wanted, to take that burden away from them because it's, I mean, making important decisions under that kind of stress is just not the right recipe for success.

There's some misconceptions out there, you know, about whether you receive the same care if you're an organ donor or not. I want to reassure everybody that that's not the case. The system itself, the medical system, I think has some issues that need to be remedied to make this a better system to achieve our goals. We don't have donation specialists in Saskatchewan. We don't have a mandatory referral process. We have a plan for DCD but hasn't been operationalized. So that's donation after cardiac death, which is a way to expand a donor pool.

We have all kinds of, I mean, you all know very well the budgetary issues that face our health regions that translate to bed, patient flow issues, that very much influence an intensive care unit and an emergency department, but typically it's an intensive care unit where a donor is going to materialize. So there's a lot of things there to be considered.

Geography I've mentioned a few times, and I think it's a big issue because we have 650 000 square kilometres in this province. And if you have a donor in La Ronge, a potential donor in La Ronge, how do you translate that to an actual donor? And we have to give that a lot of thought. Is it that the patient or potential donor comes to the team or the team goes to them? You know, we're going to have to start thinking outside the box a little bit.

So there's some things I think we could do better and differently. You know, I think public awareness has come up many times in the course of the day, I'm sure. I'm not sure — I haven't been here all day, and I apologize for that — whether or not anybody's raised the idea, boy we'd better survey and consult the people of Saskatchewan and ask them what do you think about this? What do you see as barriers? Maybe try and get a litmus test as to what the misconceptions are out there because that will inform us as to how to remedy misconceptions, how to access the minds and hearts of people in Saskatchewan to change this.

You know, I think the idea of promoting this discussion amongst families is very important. Particularly as it stands legislatively now, I think we have opportunity to perhaps change some of that, and I'll get to that. I think one of the important things in doing that will be to engage thought leaders. So you know, I think many people would see yourselves and your colleagues and Premier Wall as thought leaders, people that could go into the public domain and say, this is important, people. Let's talk about it. So I would encourage you to maybe take that on.

You know, I think we could consider a registry. 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. But it's something we can at least consider.

From a policy perspective, I suspect you've heard about opt-out as opposed to opt-in as a potential model here. And I think, you know, if we're motivated, this is an opportunity for us to go from trying to catch up to the rest of the country to starting to lead the rest of the country, at least on that issue.

You know, I think we need to further develop our organ donation organization. You know, it's a provincial program sort of, but it's run out of the Saskatoon Health Region with satellites in Regina. And everybody's employed by different regions, and there's a lot of jurisdictional issues there that I think may get in the way sometimes. And I think if you look at any high-performing organ donation transplant country — Spain, for example — you know, there are a lot of things that go into that that would, from a resourcing perspective, that we're just not there yet. So I think, you know, I think that's something we could do differently. And then there's the investment in technology, which I'll explain to you in a couple of minutes.

So I think we need to not consider, not cogitate on, but operationalize the idea of donation specialists in Saskatchewan. I think any high-performing organ transplant province, country, this is keystone, cornerstone to the whole thing. Mandatory referral, I think is an important consideration. The plan for DCD needs to be operationalized. I mean there's a lot of, you've probably heard, there are a lot of things attached to that that need to be sorted out, not the least of which is having donation specialists, dedicated organ donation organization, as I mentioned. You know, the organ donation specialists can serve the role of being this champion of transplantation within the organization, within the province, and serving educational needs of the front-line medical staff wherever they may be — they might be in a tertiary care centre; they might not — to further the cause and champion transplantation and organ donation.

Geography, I mentioned, and you know, I think we really do need to think about how we would operationalize that taking a donor from a smaller, more remote community. How do we make that happen? And that's a conversation for another day, but something that you need at least to have on your radar.

I'm going to skip that.

So this is taken from that CBS report, and you can see that we got some red squares on mandatory referral, donation physicians, and a triangle on DCD programs. Okay. We're lagging behind most of the rest of the country on these issues, so I think it's time for us to catch up because these are the things that take you — I guess I'll go back to that slide — from where Canada is to perhaps where Spain is, right? Spain is the top line there. They're 40 per million population. That's incredible. I mean Canada has a long way to go, but we have a long way to go just to catch up to our colleagues in the other parts of the country.

[15:45]

So what does it mean to increase the rate of organ donation and transplantation? What is that going to do? So it's probably going to have little direct impact on the demand, on the referrals to a guy like me, but it's going to have a huge impact on wait-list mortality, wait time for these surgeries.

I think you've gathered from previous presentations that this is not a stress-free situation for a patient. It's incredibly stressful. The uncertainty they live with is unimaginable. They're facing death all day, every day. You know, this will then translate to increased post-transplant numbers which has some cost attached to it, but it also means that you've got more people that wouldn't otherwise have been a grandparent. And I can tell you all kinds of stories about patients of mine that became grandparents because they had a transplant.

This is going to be more need for bridging technologies. And so bridging is where we take a patient who has . . . they need to be supported in an advanced way with mechanical support in an intensive care unit in the hopes of a donor coming along — and I'll talk about that a little bit more detail in a minute — and increased use of technologies to take, say, marginal donor organs and resuscitate them a little bit. And I'll explain that in a moment too.

So bridging technologies that typically get applied in the patient population that I deal with would be ECMO or extracorporeal membrane oxygenation, or using something else called a Novalung membrane ventilator. In either case these are done by . . . It's highly specialized treatment that I personally do not do. It's very expensive and it's going to become more and more commonplace because, like, the rest of the world is doing this more and more and more, and we've got to catch up. And we are, you know, this is being done more within our program. Typically that's done in Edmonton because these patients are so sick that transport is not an issue so we really . . . I spend lots of time deciding when's the right time for a patient that may be facing this to go there.

The way you, the Government of Saskatchewan, can contribute is to fund this stuff and make a concerted effort to do so. So this is something called ex vivo technology. So this is something that's relatively new but it's quickly becoming commonplace across the world. And it was really . . . although it was pioneered in Sweden, the vast majority of the development of this was done at the University of Toronto. So it's a Canadian initiative where you take marginal donor lungs and you put them in a machine that allows you to resuscitate those organs that wouldn't have otherwise been used. They would have been turned down previously and now with a bit of time and a bit of TLC [tender loving care], for lack of better description for you today, can then go on to be used and expand your donor pool.

So there's sort of two technologies. The one you see on the left is the Toronto model where they have a stay-at-home machine, and then the one on the right is called the organ care system which is a . . . it's a portable system. And that's actually the one that our program has.

So the way you could sort of participate in supporting this is that although the technology is based in Edmonton, Alberta Health Services has put a cap on how much they are willing to fund this because it's very expensive. Every time this thing gets used, we're talking about 15 or $20,000 in disposables, so it's very expensive. The machine itself, I don't even know the price, but in excess of $1 million. But there's a cap. And the way I can see it being . . . or us participating is to contribute to that to expand that cap. I might be using up my time; I'm not sure. So that's something to give some thought to, because this is something that patients in Saskatchewan have already benefitted from and we need to do our part to pay for it.

So these are my recommendations for you. I think you need to consult and survey the people of Saskatchewan as I mentioned. We need donation specialists. We need mandatory referral. We need DCD to be implemented. I would recommend dedicated funding for an organ donor organization specifically for this purpose. I think all funding for transplant, whether it's organ donation management, pre and post, should be independent of regional health authority funding because that's always subject to the squeeze, right.

And so you know, I think this is such an important issue that spans well beyond any health region in Saskatchewan. And honestly, most of my patients don't live in the Saskatoon Health Region; they live outside of the Saskatoon Health Region. I think directing the funding specifically to transplant, I think, would be a better model. Then of course the investment that I just mentioned in technologies.

So thanks for listening. I'm certainly willing to answer any of your questions if I can.

The Chair: — We'll start with Ms. Carr, but I just have a quick question. Are you planning on submitting your presentation to the committee?

Mr. Fenton: — I hadn't been planning to submit anything written, but I can certainly give you this if you wish.

The Chair: — We would appreciate that, if you do that.

Mr. Fenton: — Yes, sure. Okay.

The Chair: — So I'll just jump in right there. We'll call that HUS 25-28, Dr. Mark Fenton: Submission regarding organ donation inquiry.

And we'll start with questions with Ms. Carr and Ms. Rancourt up next.

Ms. Carr: — Great. Thank you for your presentation. So I also believe that the province of Saskatchewan is very giving in many ways and we need to be better at this. So you're not the first presenter to sit here and tell us that the province can be a leader by having a program like presumed consent or an opt-out program like that, but we do need to be better at more things.

So can you just briefly describe — because you had your little list of things we need to be doing that we're not doing — can you describe what your definition of mandatory referral would be and how we can maybe do that better?

Mr. Fenton: — Right. So mandatory referral being that . . . You know, there would be an enormous amount of education going into this, into front-line staff in health care, to identify the potential donor in the system. And then have it so that there's criteria by which they can recognize these potential donors and a trigger to then contact the organ donation organization to say, hey, we have a potential donor here. And then it would unfold from there.

You know, the donation specialist would . . . Typically they're an intensive care physician. Not always. But their job would be to help operationalize that, in my view. They wouldn't just be providing front-line care. They would be a champion and an educator within the system. Does that answer your question?

Ms. Carr: — Okay. It does. Thank you.

The Chair: — Ms. Rancourt.

Ms. Rancourt: — Thanks for your presentation. I'm from Prince Albert area and one of the most common questions I get asked is if you happen to be in a car accident beside Prince Albert and you want to donate your organs, is that something that's even a possibility? Because our understanding is that if you go to the hospital there, you could only donate your corneas.

And so I think, like you were just saying how the geographic area, that we're missing a lot of potential donors. And so I guess I have a couple questions. Like is that actually a valid situation? If a person passed away in that location, are they able to still donate more than just the corneas? Or if we have a mandatory reporting, would that help with donations from regional areas, or will still transportation be an issue?

Mr. Fenton: — Well transportation, I think, is an issue but not an insurmountable issue in this day and age. You know, I don't know the policy of P.A. [Prince Albert] Parkland or their hospitals so I really can't directly comment on what people have been told there. I would say this though, that P.A.'s not that far away.

You know, anybody that's a potential donor, you're looking at potentially eight lives saved and 75 people affected through tissue donation. That would certainly be more than cornea.

But I need to be careful because I'm really not involved in the P.A. Parkland decision-making apparatus, so I don't want to step on their toes as it were. But I don't think that . . . My view is that that a person could probably do more than donate their corneas.

Ms. Rancourt: — Okay. So when you talked about, like, there's 91 potential donors that passed away and only 10 donated within the province, do you think the difficulty of transporting potential donors to larger locations might have been an issue? Or what were some of the barriers of having the 91 potential donors?

Mr. Fenton: — Well I think the barriers are the things I kind of outlined to you. I think, not the least of which is the lack of recognition of a donor.

And then after that, I think it may be that, you know, often the conversation happens and the answer is no. That's where that survey becomes so important, right? To ask people, what are the barriers? I mean, there may be cultural or religious groups within Saskatchewan that don't agree with transplant that we don't know about. I mean, I'm not trying to hint at something here. I don't have any specific group that I'm thinking of at the moment but, you know, but we don't know until we ask. So I think that's one way to answer your question is to do that.

Ms. Rancourt: — Okay. Thanks.

The Chair: — Mr. Buckingham, and then Ms. Chartier.

Mr. Buckingham: — Thank you. I just wanted to know, you were talking a little bit about donation specialists.

Mr. Fenton: — Yes.

Mr. Buckingham: — Now I guess I'd like to know the full scale of what you're talking about. Like are you just talking about a couple of doctors, support staff? Are you talking, you know, actual physical building? Like that's such a wide open statement that I just would like a little bit more clarity of what you're really trying to say.

Mr. Fenton: — Sure. Yes, I don't envision a specific building — love to have one, but I don't envision that, per se. We're talking about a group of highly specialized, dedicated physicians that would lead this initiative. And they need to be not just in Saskatoon; we'd need some in the southern part of the province as well, in Regina, and perhaps elsewhere to kind of operationalize this. So we're talking about a group of physicians who would then have a support network around them that would include, you know, coordinators that do assessments and the other parts of the infrastructure that are part of any organ donation organization.

Mr. Buckingham: — So I'm not sure I really understood what you meant there, but as far as how many people, like as far as support staff involved, would these doctors just specialize in that, or would they also do other doctoring but then they're kind of on call to do this?

Mr. Fenton: — Well I think you'd probably, I think we'd need to look to our neighbours who have done this already to see how it's been operationalized best. I suspect you would want at least one person who is kind of the boss in charge, and probably the majority of their time would be spent on this, but then some of the others that participate would do so in a probably part-time fashion in a sense. You know, as I mentioned, they're often intensive care or emergency room physicians, so they would participate in those activities outside of organ donation, but they would also have that skill set that we need when opportunity arises. We'd have to think carefully about how we protect their time to do that effectively.

You know, I carry many, I have like this many balls in the air all the time it seems, and I'm not complaining, but at the same time it means that you have to be careful, right? And so we'd have to think very carefully about how to be sure that the time . . . that they're not just called a donation specialist, but they're given the opportunity to be one, I guess is what I'm trying to say.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you. I think, Dr. Fenton, just some clarity on that. You're speaking about donor physicians who will work as champions, work with your colleagues to increase rates, work with families. The thing that Ontario is doing, and then BC is doing, every other province has donor physicians who are champions. Just wanted . . . that's what you're referring to?

Mr. Fenton: — Yes, and making sure that we're like . . . It's not just championing the idea. It's also taking, you know, leading practices and putting them into practice and making sure we're keeping up with the rest of the world on this.

Ms. Chartier: — Like looking at missed opportunities, all those kinds of things.

Mr. Fenton: — Yes, like I mean there's enormous . . . especially initially when you're just getting into this, there's going to be an awful lot of time spent digging through medical records, looking at what happened, how can we change what happened going forward. So you know, there's a lot of time commitment there that we'd have to be mindful of.

[16:00]

Ms. Chartier: — What you've spoken about here in your proposal is very much what the transplant program has suggested around referral, or mandatory referral, and donor physicians, and separation of donation versus transplant. We've heard a little bit about all of that this morning.

Mr. Fenton: — That's a very important notion, that separation of the two, too. You know, it's really important.

Ms. Chartier: — I've got many questions here. I know my colleagues will have others. So I guess I haven't asked, I've only asked you one question here, but you're the first medical professional who's come before us who has said maybe we should be championing opt-out. Everybody else we've heard from has said, well Spain had opt-out, but they also had many other . . . It was the donor physicians and many other pieces that have gotten them to where they are. And many people who have come before us, many people who have lived experiences with transplants, have talked about the need for opt-out. But I'm just wondering from your perspective what are some possible pitfalls of the opt-out system?

Mr. Fenton: — Yes, I mean Spain is obviously a different country than Canada. They're a much more homogeneous population than Canada is. You know, they're geographically much smaller, more densely populated. There's a lot of things that'll influence their donation rates that are very different from Canada. So I certainly wouldn't argue that we can be Spain. But at the same time, you know, I think it's a reasonable thing to consider.

The pitfalls of opt-out would be, I suppose, that there is the possibility of kind of the reverse thing happening where someone really didn't want to be a donor and became one because nobody knew they didn't. But I think there's ways to build safeguards into the system so that doesn't happen. You know, I think that would probably be the most concerning one for me. Beyond that I don't see a lot of pitfalls, to be honest.

Ms. Chartier: — I do have more questions, but I'm sure . . .

The Chair: — You can continue, yes.

Ms. Chartier: — Okay. In terms of the pre-op periods that people experience — particularly around lung transplants in Edmonton, that six weeks — I represent a constituency that they're a lower socio-economic constituency. So I think about, that lens is on a lot of things that I do. So I'm wondering if you've run across people who have . . . Although a double lung transplant or the transplant is the only life-saving option, have you ever come across people who have chosen not to do it because of finances and lack of support?

Mr. Fenton: — Finances is always part of the discussion for people. I mean, I have to explain to them the potential burdens that are placed upon them. And I do occasionally have patients say to me, you know, I don't know if I can afford that. And I always say to them, I wouldn't let finances be the barrier here. There are ways around this. It might be tight, you know, but the Kinsmen Foundation has always stepped up, and others. So you know, I've had one person say, oh there's no way I'd do that for financial reasons, who then changed their mind. That leaps to mind right now.

So this is, it's an issue for people. They live at times hand to mouth and, you know, that for me is heartbreaking because they've been through so much, and we've invested so much in these people for them to be kind of living that way. So I very much sympathize with where you're coming from, but I wouldn't want to say that the people of Saskatchewan are avoiding this because they can't afford it. That wouldn't be true.

Ms. Chartier: — Okay. On that same vein I've also heard . . . So you've got the six-week pre-op period and then you come back to Saskatchewan. I had a brief conversation with someone who has a family member on the list waiting, and I've heard that it can speed things up if you can move to Edmonton. Is there any, is that . . . I don't understand how that would work.

Mr. Fenton: — That's a misconception.

Ms. Chartier: — Okay. Well that's . . . Yes.

Mr. Fenton: — So organ allocation is, you know, it's going to be independent of where the patient lives. I mean it's highly dependent on a match between the donor and the individual and a variety of other things that would play into that that really don't have anything to do with geography or place of residence.

So if you look at this right here — and I forgot to say this earlier, but Kathy Jackson from the U of A [University of Alberta] transplant program calculated some of this data for me, and I really want to say thank you to her for that — the orange bar is Saskatchewan. Between March 2010 and March of 2016, 32 of the 58 patients from Saskatchewan were transplanted. So we actually enjoy, relative to Alberta for example, a pretty good rate of donation for our patient population. There is no discrimination based on geography.

Ms. Chartier: — And I guess that's my other question around geography, so forgive my ignorance here. So in your geographic area that you showed us that you're dealing with — you've got the University of Manitoba and the University of

Alberta and then a large area — are organs being donated just coming from that geographic area? We heard about CBS and a national registry earlier today or moving in that direction. So would I ever get a set of lungs from Newfoundland for example?

Mr. Fenton: — Newfoundland's a long way away, and there's a very large and active program between here and Newfoundland in Toronto. So not impossible, but unlikely. The organs are offered out regionally, and if there's no recipient then they're offered out beyond that. That's standard. So you know, our program may get offers from even the United States at times.

Ms. Chartier: — Okay.

Mr. Fenton: — And donors from here may go beyond the borders of our geographic area that you mentioned.

Ms. Chartier: — But generally speaking, if you're in Saskatchewan or in this area, the transplants will be, the donors and recipients will generally be in that geographic region.

Mr. Fenton: —Yes.

Ms. Chartier: — I'm just trying to understand all of this. Sorry. So again the conversation around a national registry and a provincial registry and what Alberta and BC are doing . . . I failed to ask some questions of CBS this morning, and I know we're asking, we've asked them some written questions now. But I don't think I understand the whole national registry piece and what other provinces are doing around registries. And that hasn't come up . . . It's come up from patients or people who've experienced transplants or are waiting, and it hasn't been a big piece of the medical professionals who have presented. But can you give us a little bit of a sense of the landscape around registry? And I may ask you a few more questions, but help.

Mr. Fenton: — I mean there are registries in other parts of the country, as you mentioned. And I think that the impact that they've had, the biggest impact they've probably had is on public awareness. Having said that, I would recommend looking at Trillium in Ontario and their model because they've been very successful. And I've never worked there, so I can't give you a lot of insights into their sort of inner workings at all. But I do know that in other parts of the country where registries have been introduced, you know, the rate of uptake from the general public has been, relatively speaking, low. So I'm not sure . . . When I was saying I'm not sure that's the way to go, the main reason was is I think some of the other things would be bigger impact interventions.

Ms. Chartier: — So the data doesn't support it, but it's a good education tool. We've talked a lot about awareness and education and keeping it or getting organ donation in the public eye, and that would be a tool in terms of getting that in the public eye.

Mr. Fenton: — Yes. And sometimes it's a challenge to link a registry to a potential donor, right? I mean, there's a lot of information-sharing issues there that really have to be managed carefully. So if we were going to do that in Saskatchewan, I would recommend it be linked to their personal health number so that it's part of the eHealth profile of the patient so that it's immediately apparent to somebody that's looking after them in the hospital setting.

Ms. Chartier: — Well thank you for that. I think just one last thing, which is a comment. I think your recommendation on doing a survey is a very good idea. I think sometimes we assume what the barriers are. Whether we're individuals in the public or professionals, everybody assumes we know the answer and then can be quite surprised when we actually talk to people and find out what the barriers really are; like we stick our finger in the wind and think, oh that might be it.

But I think your point around surveying people in Saskatchewan and asking what the barriers are, that's the first we've had that suggestion, but I think that that's a very good one. Thank you for your time here today.

Mr. Fenton: — Thanks.

The Chair: — Seeing no further questions, we're going to take a very short recess while we get ready for our next presenter. And I want to thank you for taking the time to present to us today. Thank you very much.

Mr. Fenton: — My pleasure. Thanks for having me.

[The committee recessed for a period of time.]

The Chair: — Well good afternoon. Our next presenter is Mr. Jim Angus. I'd like to welcome you to the committee today. Before you begin your presentations, if you could introduce yourself, and if you're speaking on behalf of an organization, please state your position within the organization represented. And if you have a written submission, please advise that you'd like to table a submission. Once this occurs, your submission will be available to the public. Electronic copies of the tabled submissions will be available on the committee's website.

And once your presentation is completed, committee members may have questions for you. I'll direct the questions and recognize each member that is to speak. Members are not permitted to engage witnesses in any debate and witnesses are not permitted to ask questions of the committee. Our agenda again allows for a 30-minute presentation, followed by a 15-minute question-and-answer period. And, sir, if you'd please start your presentation.

Presenter: Jim Angus

Mr. Angus: — Hi, my name is Jim Angus. I'm from Harris, Saskatchewan. Today I am not representing anybody, and I did provide a written submission that I believe you all have. Okay? I have drawn the dreaded end-of-the-day submission here and I suspect you're all thinking to yourself, I hope this guy doesn't drone on forever. But I'll do my best.

The Chair: — You have the time you need, sir. And we have the time, so we'll . . .

Mr. Angus: — No problem.

The Chair: — Take the time needed.

Mr. Angus: — Okay. Good afternoon. For starters, I would certainly like to thank the committee for the opportunity to address you this afternoon.

I'll start by giving you a very short background of my personal transplant journey. In 2002, I was diagnosed with liver carcinoid, a fairly rare form of liver cancer. Surgery and various treatments followed but the only true option for a cure and a chance at life was a liver transplant. I was listed for transplant at the University of Alberta early in May of 2006. I got my call a month later, receiving my new liver on June 4th, 2006. I adapted very well to my new liver and was out of the hospital in a week and returned home to stay within a month. And I celebrated my 10-year anniversary about three months ago.

I think we have a great opportunity as a province to lead the way with regards to improving the rate of organs available for transplant. As you know, our record in Canada is very poor overall, and is absolutely abysmal in Saskatchewan. I don't believe that Saskatchewan people oppose organ donation. On the contrary, Saskatchewan people are generous and caring in nature and are always willing to do the right thing.

Our current system of placing an organ donor sticker on our health card is just not working, as indicated by the low donation rate in Saskatchewan. At the time of an accident or donation opportunity, it is often overlooked and neither the family nor the health care professionals think to check. This is very understandable given the level of stress and distress at a time such as this. Consideration for organ donation often comes after it is too late.

Part of the problem in Saskatchewan is that many of the accidents that might result in organs being made available for transplant occur in rural Saskatchewan. And I think it would be fair to say that most rural hospitals are not trained or equipped to deal with families regarding organ donation at the time of the death or pending death of a loved one.

In our major cities we have health care professionals who are better equipped to deal with families at such a time. But given the very low number of organs made available for transplant, it is obvious that, even in our major centres, the message may not be getting through.

Most families, given the opportunity, would like to see something positive arise from the death of a loved one. A good friend of ours lost his life in an accident less than a year ago and his wife told me a number of months later that the possibility of donating her husband's organs was never discussed, and she wished that they would have had the opportunity to do so. It should also be noted that he did have his donor sticker on his health card. In the chaos surrounding the accident, it was never considered. As noted earlier, it would have allowed something positive to occur from a tragic event.

This past January we all witnessed a senseless tragedy involving the Jordan Van de Vorst family when their entire family were lost due to a drunk driver in an accident just north of Saskatoon. This must have been an unbelievably terrible nightmare for their surviving families but two very important positive events evolved from this accident.

Firstly, as many as 32 lives may have been saved through the donation of organs so graciously provided by the Van de Vorst families. Jordan Van de Vorst's father, Louis Van de Vorst, went to great lengths to thank the organ donation team in Saskatoon and noted the importance of making some good evolve from a tragedy such as this.

Secondly, due to the magnitude of this accident and the media attention to it, there has been a significant increase in the awareness of the importance and value of organ donation. As a result of this terrible loss, more people are understanding and appreciating the benefits of the opt-out system for organ donation. Hopefully the Van de Vorst families will find some solace in these two positive outcomes.

Organ transplantation works. There is no question as to the benefits surrounding organ donation and organ transplantation. As I noted earlier, I received my new liver in 2006. In June of 2011, the University of Alberta liver transplant team celebrated the 1,000th liver transplant carried out at the U of A. To commemorate the event, a celebration was held and concluded with a large banquet. A significant number of liver recipients and their families returned to Edmonton and attended the function.

The benefits to the organ recipient is obvious: a second chance at life and the opportunity to continue as productive members of society. But it is also important to look at the effect it has on other family members and friends. I remember very well talking with many people that evening and seeing the gratitude in the eyes of the family members who still had their dad, their mother, their brother or sister, their grandpa in their lives. What value do you put on this?

On a personal note, I lost my brother to cancer in 1990. Without the option of transplant, my mother, who is now 100 years old, would have had to endure seeing another one of her sons laid to rest.

The event in Edmonton I mentioned was very uplifting. Every liver recipient had their liver transplant number shown on their name tag, and I was number 883. During the evening, a number of recipients spoke, including number 3, who had received her liver in 1989. At that time there were many more challenges involved with the surgery, and she spent most of the year in the hospital before becoming stabilized.

Over the years, the drugs have improved greatly and the procedure has been improved dramatically. At this point in time the success rate is very good, with survival at five years in the average range of 78 out of 100 transplants. And that figure is specific to liver transplantation.

When you consider all organs, at any given time in Canada, there will be approximately 4,500 people on the waiting list waiting for organ transplantation. Of these, about 25 per cent will die while waiting for an organ to become available.

These deaths need not occur. The weak link in the whole process is the shortage of donor organs, and this is a problem which could easily be rectified by initiating the opt-out system for organ donors.

We realize that there are some groups who for religious, cultural, or personal reasons are not in favour of organ donation, and it is very important that we respect their views. In light of this, there should be an easily accessible method of opting out of the system if you do not wish to have your organs used for transplant after your passing. Hopefully this would address the concerns of those not wishing to make their organs available.

I am very passionate about the benefits of organ donation and the transplant process, and over the past 10 years have had the opportunity to speak to several thousand people to promote organ donation. I am sure the large majority of people support the idea and would wish their organs to be used after their death, but unfortunately they rarely do — in large part to the reasons we have discussed above.

This can be remedied. In my mind, there's really no downside to moving to an opt-out system. There will be significantly more organs available for transplant, which result directly in saved lives. The pressure is removed from families having to make the decision at the time of death as the decision has already been made by their loved one by the fact that they had not opted out. Health care professionals not required to counsel families with regard to possible organ donation at a highly stressful time for both these professionals and the family involved. And provision of an easy method in place for those wishing to opt out to protect their rights.

These are but a few of the benefits involved if we move to an opt-out system. As I noted at the beginning of my presentation, we have a great opportunity before us to lead in the area of organ donation and organ transplantation. A vast majority of Saskatchewan residents, if taken the time to consider organ donation, would certainly agree to become a donor.

I never speak about organ donation without publicly thanking my donor family who made the decision to have their son's organs donated after a very bad accident back in 2006. There are six of us alive today because they chose to make that decision, and I hope that knowledge has brought some comfort to my donor family over the past 10 years. In that 10 years, I have seen my daughters happily married. We brought six more grandchildren into our family for a total of seven. I've retired and I'm enjoying life to the max. This would not have happened were it not for the gift of life that they so generously provided to not only me, but also to my family. And to them I say, thank you.

I'll conclude by asking that every resident in this province, and I would say every member of the committee, ask themselves this one simple question: 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.

I'd like to thank you for your time this afternoon and I strongly urge you to recommend the initiation of the opt-out system for the residents of our province. I truly believe it's the right thing to do. Thank you.

[16:30]

The Chair: — Well, thank you very much for your presentation, sir. I want to put in your submission, HUS 26-28, Jim Angus: Submission regarding organ donation inquiry. Are there any questions? Well I, then . . . If none of my colleagues have one, I'm going to open the door with, what does an opt-out option look like for you? We've heard different versions of it.

Mr. Angus: — How do I foresee it happening?

The Chair: — Exactly.

Mr. Angus: — I know there are some places in the world where it's been done. It's kind of cutting edge, but basically everybody would be considered a donor unless they opt out. And I look back a number of years ago when the province brought in the no-fault option for auto insurance. When they did that, everybody was deemed to be in no-fault unless they declared that they didn't want to do that. I think you would need something like that.

Certainly there are groups of people for whatever reasons, like I mentioned, whether it's cultural or religious or personal reasons, and you would want to make sure that these people had a very easy route to opt out. And I think something as simple as sending out . . . When the program starts, you send out a form with a return postage-paid envelope, a little bit of background on the program. In or out, and back in.

But so often when you look at the number of . . . The last speaker was talking about the number of possible donations that we have in this province and the low number that actually occurred. That's tragic, because until I had my transplant I certainly had my donor sticker on my card but I never gave it much thought. I mentioned that night in Edmonton at the banquet. When you sit in a room with several hundred people, and every one of them are there because some family at a time of terrible distress made that critical decision to allow those organs to be available for transplant, it's . . . you can't explain it. I mean those people are there alive today just because of that one fact.

And the science is certainly there. They've come so far with the quality of the transplant and the success rates. Talking about the University of Alberta cutting-edge technology there, I can tell you some stories on some of the things they've done, but I'm not going to take the time today. But I certainly feel it's the right thing to do.

After I had my transplant a lot of my friends said, you know, I never really gave this a lot of thought, and since you've had it we've put the stickers on and told our family and whatnot. But if you don't have that personal contact with somebody, yes, you think it's the right thing to do but it just doesn't happen; you don't talk to your family about it. That's why I think the opt-out system, it makes people think about it. And if you don't want to participate, make it easy for them to decline it. But I think it's the right thing to do.

The Chair: — Thank you. I see Mr. Buckingham has a question.

Mr. Buckingham: — As far as your opt-out program, now you see it as a completely stand-alone program rather than tying it with, like, the licencing program through SGI or through doctors. Would you prefer to see it just as a stand-alone?

Mr. Angus: — I'm not sure of the mechanics of how it works in Sask Health, but what I would see is that that database is held probably at Sask Health, and if there's an accident in Assiniboia, Saskatchewan and the first thing they do is just check the database — this person's organs should be available.

We're lucky in this province now to have STARS that can, in some of these cases . . . There again, one of the earlier speakers talked about distance. STARS has made a huge difference in shrinking that distance and that would be a big help too. But I think it has to be that central database, in my mind, makes most sense to have it supported by Sask Health. And if there is an accident or a chance for organ donation, key it in; yes, this person has not withdrawn and their organs are available.

Mr. Buckingham: — All right, thank you. And I really appreciate you taking the time to give us this submission and it's always important that people . . .

Mr. Angus: — I'm very passionate about it. Like I said, through the things I've been involved with over the years, I have had the opportunity to speak to a lot of people about it. And I think education is a huge item, and we do that through this.

Mr. Buckingham: — Thank you.

The Chair: — Mr. Docherty has a question.

Mr. Docherty: — Thanks, Mr. Chair. Thanks, Mr. Angus. Thanks for joining us here today. We had earlier presentations in regards to families being able to override your opt-out and I'm interested in your thoughts. Have you put any thought into how that would look or how we could actually assist in getting organ donations?

Mr. Angus: — My personal feeling is if the family, at the time of death, if the family is really strongly opposed to it, I think that should override. But I think what it'll do, the fact that the person, the deceased, had not taken the effort to take their name off the list, I think that sends a fairly strong message to the remaining family as to what the wishes of the person were.

And for sure, I mean the last thing you'd want to see is a fight in the hospital between a grieving family. If they say no, it's no. But I think that, like I indicated, the fact that the loved one had not opted out should send a message to them of what their wishes were.

Mr. Docherty: — Okay. Could I have a follow-up?

The Chair: — Do you have a follow-up?

Mr. Docherty: — Yes. Okay, so would you also . . . What are your thoughts in relation to individual organs? Would there be opt-out? I mean do people have the opportunity to say no, I'll donate this, but I won't donate that?

Mr. Angus: — That's the way that the initial card years ago, when they came with your driver's licence, that's what they were: my whole body, my body to science, you know, eyes, liver, and you check it. I don't know. I guess there again it's a personal thing, but you're not going to use them. And I go back to sitting in that room. A lot of the transplant friends we've made, you know, those people are here because somebody provided those organs for transplantation. And I mean if that hadn't happened, they would not be here today.

Mr. Docherty: — Okay, thank you.

The Chair: — Well thank you very much for your presentation today, Mr. Angus. I really appreciate you taking the time to come and speak to us.

I need a motion of adjournment from one of our members. Mr. Buckingham. So our committee stands adjourned until 9:45 a.m. tomorrow morning.

[The committee adjourned at 16:36.]