



STANDING COMMITTEE ON HUMAN SERVICES

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STANDING COMMITTEE ON HUMAN SERVICES

Mr. Greg Lawrence, Chair
Moose Jaw Wakamow

Ms. Nicole Rancourt, Deputy Chair
Prince Albert Northcote

Mr. David Buckingham
Saskatoon Westview

Ms. Danielle Chartier
Saskatoon Riversdale

Mr. Mark Docherty
Regina Coronation Park

Mr. Muhammad Fiaz
Regina Pasqua

Mr. Roger Parent
Saskatoon Meewasin

Hon. Nadine Wilson
Saskatchewan Rivers

**Public Hearings: Improving Organ and Tissue Donation
Rates in Saskatchewan**

[The committee met at 13:00.]

The Chair: — Good afternoon. Welcome to the Standing Committee on Human Services. I'm Greg Lawrence, Chair of the committee. I'd like to introduce the other members of the committee. We have Mr. Buckingham, Mr. Fiaz, Mr. Parent, Ms. Chartier, Ms. Rancourt. We have substituting for Ms. Wilson, Ms. Carr; and we have Mr. Gene Makowsky subbing in for Mr. Parent today.

Prior to today's proceedings, I have three documents to table with the committee. We have HUS 8-28, Jerome Cardiff: Submission re: organ donation inquiry, dated August 20, 2016. We have HUS 9-28, Ronda Wedhorn: Submission re: organ donation inquiry, dated August 22, 2016. And we have HUS 10-28, Ministry of Social Services: Responses to questions raised at the June 21 and 22, 2016 meetings.

Today we are holding public hearings on improving the rate of organ and tissue donation in Saskatchewan. On May 19, 2016, the committee was issued the following order from the Legislative Assembly:

That the Standing Committee on Human Services, in accordance with rule 149 of the *Rules and Procedures of the Legislative Assembly of Saskatchewan*, shall conduct an inquiry and make recommendations to the Assembly respecting improving the rate of organ donation in Saskatchewan; and

That the said committee shall hold public hearings to receive representations from interested individuals and groups and report its recommendations to the Assembly by November 30, 2016.

Over the last few months the committee planned the inquiry process, deciding on the time and location of the meetings as well as the scope and focus of the inquiry. The committee agreed that stakeholders and the public should focus on the following question: how can the Government of Saskatchewan increase the rate of organ donation and improve the effectiveness of the organ and tissue donation program in Saskatchewan?

The committee has been scheduled for four meetings on the topic: September 6th and 7th at the Legislative Building in Regina, and September 12th and 13th at the Hotel Radisson Saskatoon in Saskatoon. All the committee's public documents and other information pertaining to the hearings are posted daily to the committee's website. The committee's website can be accessed by going to the Legislative Assembly of Saskatchewan's website at www.legassembly.sk.ca. Check the website for further information on participating television service providers, their broadcast areas and channels. The committee proceedings will also be live-streamed on the Legislative Assembly of Saskatchewan website and the archived video of the proceedings will be available.

I would like to advise the media and general public of the

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

Before we hear from our first witness, I'd like to advise the witnesses of the process of presentations. I will be asking all witnesses to introduce themselves and anyone that may be presenting with them. Please state your name and, if applicable, your position with the organization represented. If you have a written submission, please advise that 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.

I will ask you to proceed with your presentation. 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 the witnesses in 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.

I'd like to now welcome our first presenter, Charlotte L'Oste-Brown. Hopefully I said that right. Please introduce any co-presenters you have with you, and you may begin your presentation.

Presenter: Charlotte L'Oste-Brown

Ms. L'Oste-Brown: — This is Sherry Hornung. She's with me today as nurse practitioner. I have been a patient of hers and we've become . . . working together in promoting organ donor awareness. And I'm Charlotte L'Oste-Brown.

I'd just like to say good afternoon and thank you for allowing me to come here today to present my story on how detrimental it is to have a registry set up. I've got more of a story on why I think it's important rather than solutions, but hopefully with the story it will help answer some questions. And I'm going to read it because I don't want to lose my place. I know what it's about.

So my story is, I was living on a mixed-farm operation, raising two energetic daughters. I coached ball and I was active on the school board and in the community. And then in 2003 I got the disease pulmonary fibrosis.

The conditions of this disease really didn't bother me in the first few years, but I noticed I had to gradually start giving up physical jobs. I owned and operated a 15,000-square-foot greenhouse for 18 years, so that came to an end immediately. Cutting grass. I don't remember the last time I actually ran, to be honest with you. Lifting and quick movements, dancing, I gave up curling, pretty much everything. Except now today I pretty much just exercise trying to keep myself strong for the transplant.

I have downsized to a room-and-board situation from maintaining a two-acre yard and a 13-square-foot, two-storey home. My career has changed to an advertising consultant for *Prairies North* magazine. I work out of my home.

And honestly I have to say I took, I believe, everything in my stride. But you know there's a lot of inner frustration, you know, waiting. But I did what I was advised to do and what I read about.

The changes happened gradually. I started out, of course, I had 100 per cent use of my oxygen and went down to 68 per cent in about a 10-year time frame, or I guess that would be over about a 12-year period.

But then in 2014 in August, I went down from 68 right down to about 38 per cent. I got an infection and that's when things really started happening. It was a pretty scary time. And I came out of it and the doctors then at that time started procedures to get me on the list. And you can't believe how happy I was but I wasn't really . . . I didn't have any idea what was ahead of me these last couple of years.

So I've been to Edmonton for my six-week pre-op. And that was November 2015, and I had to get a place to stay there. And then during that time I learned I had to have funds in order for a three-month stay with a 24-hour caregiver, groceries for two, pay my rent in Regina while I would be in Edmonton. And you know, so I did all that, got ready for, you know, this double lung transplant.

And now I've been on the top of the list since December 1st, 2015. And every time I have a doctor's appointment, that's what they say: you are at the top of the list, and we just have to wait for the correct, somebody with the correct . . . who has given the organ, the gift of life, my exact size, height, size of my chest, and blood type.

I have to say I get a little angry from time to time. You know, you wake every day . . . I feel I've jumped every hoop possible to survive this far. I was told when I got diagnosed that seven out of ten people die within 10 years, and I needed to look after myself until an organ transplant became an option, and that organ transplant option would come when I was on my last breath.

And I guess I've done that, and in the last two years I find it actually very frustrating. I'm attached to a 50-foot hose, have to go everywhere with oxygen. It's very stressful. It's not just pulling the oxygen tank around. There's a lot of stress that goes with that, not to mention that I go out in my condition and I advocate for the gift of life as much as I can, and I've been doing that since December 1st. And I guess the reason why is very obvious, you know. Forty-five people, approximately, died last year waiting for organs. That's two out of every six, however you want to look at it, 33 per cent. Like to me it doesn't even make sense now that I'm in this position, you know. Like I wonder why something hasn't been done before.

So typically I go to bed every night and I get up in the morning hoping I haven't choked through the night because that can happen due to a lot of coughing. Then I wake up every day, and I think, geez, maybe I'll get that call today. Maybe I'll get it

right now. My phone is on low, but maybe I'll get it right now. And you know, and then you have to have this bright, cheery outlook, you know, to carry on for the day. God, that's a real roller coaster, you know, and it's for everybody waiting. It doesn't matter what organ you're waiting for, right? You're just waiting for somebody to give that gift of life.

So I guess, you know, ultimately when you come out of pre-op, which I did in December, you're at the top of your game physically, mentally. It's a great program, you know. I guess the result would have been great if there were some lungs. I could have just gone and had it that time, right?

So now I'm waiting. So in the wait, you go home and you're asked to look after yourself, to keep in shape. Here I am nine months later and, you know, there's a lot of days I feel like now I've been . . . I have to learn to come home to cope how to deal with death. And that's the honest truth. I have no other way to say that. And I have a great support system. They recognize for me to get out. They're with me. They give me a phone call. This gal, Sherry, drove in today for four hours to be here with me today, you know. And I've been doing, you know, what I can to get out and doing public speaking engagements.

So I guess now I'm at the point where I want to share with you what I've been hearing about, the public engagements on the concerns. And what I hear is, you know, they'll say, oh you mean that little piece of paper that comes with your driver's licence with that little red sticker? I say yeah, that's the one I'm talking about. And I get a typical response is, yes, well that's sitting on my desk and yes, I've got to fill that out. I will say, yes, if you want to be an organ donor, a donation, and give someone the gift of life, do it today. Because people waiting like me, a lot, we don't have until tomorrow.

And people aren't filling out the card or even putting the sticker on the card. And to me that's not a time-consuming task, but obviously it is because less than 1 per cent of the people in Saskatchewan are doing it. So I guess in trying to decide a system, you know, what needs to be done, I guess it has to be something very simplistic. And then I hear people saying, well you know, all you need to do is get something done online. So my question is that the same people that aren't filling it out and putting the sticker on the health card, would they be taking that time to go online? And you know, it's a real Catch-22 for me when I hear what people are saying. The job ahead is a very big job.

Taking note that people that are not donating in this province, also a huge age group is over 65, and then you get, you know, over 70, and a lot of people don't have their driver's licence. And they believe, they're the huge portion that believe they are too old to donate organs. And I went to an independent living senior condo last week; there was about 200 people. There was a group of about 15 met me at the door and said, you know, Charlotte, we're too old. I don't know . . . That's why there's not very many people here. We're just too old, you know, to donate our organs. And I said, well you know what? I'm here to let you know how valuable each and every one of you are. And they just thought they . . . And I find that's a general consensus from people I've been talking to.

I'm happy that my doctor and a representative of the Canadian

Transplant Association have encouraged me to advocate. The advocating, you know, will be never ending. And I'm advocating and in desperate need. But I have to say I find it tiring and quite emotional at times. But you know, I keep doing it. And the reason, I realize, why I keep doing it is because, and I just said to Sherry earlier, right now I believe that people like me waiting, we make an impact. We're not a pamphlet that someone is going to pick up and read. We're real, and this is what's happening. We are waiting. And not everybody has the luxury of getting out like I do, or maybe likes to talk as much as I do either so, you know, it helps.

So in my travel, I guess I find education . . . People, it's not that they don't want to give the gift of life. It's the education I feel that needs to be out there to understand the necessity of it. And I don't know the answer to a successful, efficient registry. I don't. But I'm sure there will be a lot of things that come into effect when planning it. And you know, I guess I think of the cost, obviously comes into effect.

[13:15]

But when I think of the people that are waiting and can't do any physical work . . . I'm fortunate. I sell advertising out of my home. But with even that, the mental stress, it's hard to get going. And anybody that is waiting, a lot of people, they have to quit their jobs. And I need to keep working. I'm single. And you know, I've jumped the hoops to try and apply for different services, and I fall through the hoops.

So what do we need to help? I don't know. A few people have said that, for instance, like I would need care maybe, maybe how long depending I have to wait. I'd be in the hospital. And at that time, everything is starting to build up. The cost is great.

So other stories, there's lots of other stories out here about life saving, waiting, sure. But for sure I feel in planning a registry, we have to have an easy way for people to give that gift of life. And I do hear in my travels people talk about giving an opt-out program. I hear that as well. And something I noted yesterday when I was working on this, I thought to myself, you know, if I was asked if I wanted to give the gift of life as often as I was asked for my next of kin and confirm my address at places like the doctor's office, the eye doctor, any banking . . . Just try and retrieve your SaskTel password and see the information you need to give, you know?

Like I have to wonder, are there businesses that would be wanting to get involved, take all that documentation and then send it, you know, to the government after and work along with pharmacies maybe? Like places that have, you know, they cover all our demographics. I have to wonder if maybe that might be an option, you know? It's just one more box to tick off when you're asking a question.

For me, well I'm praying for a real quick, efficient outcome on educating Saskatchewan people for registry or educating or a program put together for both. So many people don't have tomorrow.

And I guess the last thing I need to say is that I felt it is important for this panel to hear stories of what the wait is like and hear first-hand. It is extremely difficult and it actually can

become quite debilitating, and suicide becomes an option for people waiting. There is a real urgency to get something in place to increase the awareness for the gift of life. And with that, I'm done with what I have to say.

The Chair: — Well thank you very much for your presentation and speaking to us from the heart. Now are there . . . do our committee members have some questions? Start with Ms. Chartier.

Ms. Chartier: — Well first of all, thank you so very much for your time and telling us a little bit about your story and your experience.

Just in terms of the process, I actually had a friend who had a double lung transplant a few years ago. But that piece that I always find interesting, so you've got the six weeks in Edmonton for the pre-op. As a single person, how . . . and then you'll have to go back for the transplant and then you have to wait, I understand. Do you mind me asking how you manage that? Particularly as a single person, I'm sure it becomes even more challenging.

Ms. L'Oste-Brown: — Well when I went for my six-week pre-op, I found a bed and breakfast right close to the hospital. And what should have taken me probably a seven-minute walk took me 20 to 30 minutes. I would turn my oxygen up and just go, because we'd have to be there at 7 in the morning and we would have a lot of counselling on what things would be like. So that was for six weeks straight. So I went but in the meantime my daughters came up to visit. I had some friends come up and visit to help, you know, get through the time and a great support for me. And they would come to the gym with me and of course we'd go to the West Edmonton Mall to bide a little time. They've got really good scooters there for me.

The thing is it's expensive. I mean I had to find a place and pay for it, yes. Now when I go back, I have had somebody offer to come with me who is a retired lady, said she would come with me, you know, for the three months. We will be staying in a suite across from the hospital. Yes, just like I said we have to get groceries. She's there, you know, to support me through. And I have to be in Edmonton because we have to check in I believe, I understand, every day our blood work and everything has to be checked to see that we aren't in a state of rejection. And I guess that's something, you know, that's truly expensive. And I haven't talked to anybody who has that kind of money in their back pocket, you know, to do all that. There's nothing in place for that. And you know, it'd be nice to be able to come back to Saskatchewan and go through that, you know, process here.

Ms. Chartier: — For sure. Well thank you.

Ms. L'Oste-Brown: — Did I answer your question?

Ms. Chartier: — You did, yes.

Ms. L'Oste-Brown: — Okay.

The Chair: — Ms. Carr.

Ms. Carr: — Thank you. Thank you so much for your

presentation. You talked about the difficulty with the registry and, you know, the things that people just don't take the time to do. So I heard you say something about an opt-out program. What would that look like to you or what would that mean to you?

Ms. L'Oste-Brown: — Well I guess from people who've brought it up to me, it sounds like they would like to have everybody registered to donate their organs because . . . I suppose newborns would be a little different, you know. But again there'd have to be, I guess, a registry in place for everybody saying that they're donating. And then if you didn't want to, fill out the . . . maybe still send the cards the same. And if people didn't want to be in, then they would have to send the cards in. I don't know how that would really look but there would still have to be a registry in place, you know, perhaps the same it is now and just have people decide that way. I don't know.

Ms. Carr: — So if I understand you correctly, everybody's a donor until they choose not to be a donor.

Ms. L'Oste-Brown: — Exactly.

Ms. Carr: — Okay, thank you.

The Chair: — Questions?

Ms. Rancourt: — Again thanks for your presentation. Like I said before, I read your article in that magazine and that gave me a lot of background information as well about your situation. And so the things that we're going to be really paying attention to with these presentations is to come up with a plan on how to increase organ and tissue donation within Saskatchewan.

And I know some of the things that you were saying, what I heard was that you really think education is something that's important that we need to do to increase the amount of people who are registering. So in what ways do you think we could do a better job with educating the people of Saskatchewan?

Ms. L'Oste-Brown: — Well I've only been out doing public speaking since December 1st. I guess in that short time, I've found that in the short time I've been going, I've made an impact on awareness. So there could be different ways. There could be people like myself waiting. Perhaps we could go into schools. You know, there's a large demographic to meet there. Perhaps, you know, every chamber in the province could welcome some education awareness, just trying to reach all the demographics. I'm just saying that I notice that I make an impact because of the situation I'm in, but it could be after I get my lungs and I wouldn't have the tank. And it could be people like yourself that could go into schools. It wouldn't have to be people waiting.

The Chair: — Mr. Buckingham.

Mr. Buckingham: — Hi, and thank you as well for your submission. It's very important that you do this. And I'd kind of like to know, since you're on the front lines out there getting the opinion from people, do you think it's an awareness issue, or maybe they just don't want to commit to being an organ donor?

Like you would, you know, being out there talking to people, do you think it's just an awareness issue or is there more to it than that?

Ms. L'Oste-Brown: — Well I'm going to refer to when I was in Shaunavon and did a speaking engagement there for a fundraiser, and I think there was 170 people there that night. I believe what happened was the numbers were . . . I think there was about 10 people maybe that knew about organ donor, that were aware of organ donation and how to do it. I had sheets with me with the sticker on. They were all used up. From that night and other nights like that, I gather that people just did not realize the importance. And there was people in the audience crying, and they weren't crying for me. They had tears in their eyes because they felt like they just didn't know, and they felt, well they should know. And you know, so I can only assume, you know, we need to let people . . . educate people on how important this is. And that's from my experience being out from just December.

The Chair: — One more?

Mr. Buckingham: — Yes. I just wondered, so if we went through a driver's licence program, would that have caught, of those 170 people that were at that event, would we have caught most of them if . . .

Ms. L'Oste-Brown: — You'd have caught all of them.

Mr. Buckingham: — Okay.

Ms. L'Oste-Brown: — I can't remember anybody that would be there that wouldn't be driving that night, you know, I mean wouldn't have a driver's licence. So in answering your question then, I guess it comes back to, I believe, we need to educate people on the awareness of it, the importance.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you. I've got a couple different questions, and I know you're not a health care professional, but I'm just wondering, in your travels . . . There's something that twiggged with me when you talked about age. About a year and a half ago or two years ago, the legislature had a bill before us on organ donation and how to improve it. And in my conversations with the organ donation program here, one of the things that I heard and had learned is that age really isn't a factor. It's about health.

And so I know you can't speak to that directly as a health care practitioner, but you did mention it. It was fascinating to me. And often physicians don't realize that patients can be good donors as well. And that's . . . Have you heard that in your travels? Physicians, your general practitioner or someone that is working with someone who doesn't have a lot of expertise in organ donation doesn't realize that some of their patients, their elderly patients, could in fact be good donors.

Ms. L'Oste-Brown: — I guess all I hear in my travels is that people that are elderly, they just feel they're just too old to donate, and that's what I've heard. I haven't heard anything regarding health professionals, what they're aware of and what they're not aware of. That I really can't answer. No, I don't

know that.

Ms. Chartier: — For sure. I'll save those for when we have the program before us.

Ms. L'Oste-Brown: — Yes.

Ms. Chartier: — I believe they'll be here next week.

But a second thing that maybe you've heard, I understand even if you sign your organ donation card and put the sticker on the card, that that doesn't guarantee you will be a donor. There are often times that family members, if you haven't shared your wishes with family members . . . I have two daughters, for example, and I believe that they know that I've put my sticker on. But when push comes to shove, when that decision has to be made, sometimes family members, even if you've been a willing donor or indicated that you're a willing donor, that that doesn't always mean you will be a donor if family members decide that they . . . Because people have all different kinds of discomfort with it when it comes to that moment. But have you heard that in your travels as well?

Ms. L'Oste-Brown: — Yes. Right now, I'm under the understanding that family can override the wishes. That's why usually when I start a presentation, it's all about the sticker and it's all about talking to your family because they do need to know. And I don't know of anybody personally who's, you know, had offered the gift of life and their family has said no. I haven't heard that in my travels. But yes, definitely, right now I understand family can override it. So it's important, really important to talk to friends, family, you know.

I have run into one lady who said, well she's got it in her will. But you know, that maybe doesn't help the immediate issue, but you know, the thought was there that that's what she wanted to do.

[13:30]

Ms. Chartier: — Thank you very much.

Ms. L'Oste-Brown: — Thank you.

Ms. Chartier: — Thanks.

The Chair: — Are there any other questions? Well, I want to thank you very much for your presentation and starting us down our path to figure out how we can do a better job serving the people of Saskatchewan in this. So thank you for your time. And I don't know if wishing you luck in your travels is the best way to do this, but our, especially my family's, thoughts and prayers will be with you.

Ms. L'Oste-Brown: — Well thank you so much. I've spoke at a lot of different events. I never expected to be at one like this, but thank you very much.

The Chair: — Okay, thank you. We're going to take a short recess while we wait for our next presentation this afternoon.

[The committee recessed for a period of time.]

The Chair: — So good afternoon. We're back. I'd like to table the document HUS 11-28, Charlotte L'Oste-Brown: Submission regarding organ donation inquiry, dated September 6th, 2016.

And we'll now move to our next presenter, Mr. Ronald Kruzeniski, the Information and Privacy Commissioner. Welcome to the committee today, sir. I would ask that you introduce yourself and anyone else that may be presenting with you, and please state your name and position within the organization again. And if you have a written submission, please be advised if you'd like to table that. 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.

I will ask you to proceed with your presentation 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 again are not permitted to engage the witness in 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 sir, if you'd please proceed with your presentation.

Presenter: Office of the Saskatchewan Information and Privacy Commissioner

Mr. Kruzeniski: — Well thank you, Mr. Chair. My name is Ron Kruzeniski. I am the Information and Privacy Commissioner. And with me today and my co-presenter is Ms. Diane Aldridge who's the director of compliance in the Information and Commissioner's Office. I thank you for inviting us to make a presentation, and a presentation on the very important issue of human tissue and organ donations.

Our presentation is intended to be fairly short, and I hope that allows lots of time for questions from members of the committee. We have sent our submission electronically to Mr. Park. We've also come with print copies that are available today, and those have been distributed.

I understand this is a very difficult issue, and I appreciate the committee taking on the task of considering the options that are available to our province. We will not be commenting on the options, for neither Diane or I are experts in the area of organ transplants. And as you can appreciate, our expertise is more so in the area of access to information and protection of personal information.

[13:45]

We do still acknowledge the importance of your deliberations and the issue. For me personally, I had a very special aunt who had a kidney transplant a long time ago, and at the time she was the oldest person in the province to have had a kidney transplant surgery. And I saw the significant lease, new lease on life it gave her. So certainly we understand the significance of the issue to those that are waiting in hospitals for organs and, you know, hoping to have a new lease on life. So I wish you the absolute best in your deliberations. And now I'll start to gradually focus in on what we want to talk about today, and we're pleased to make some recommendations to you.

Our business is personal information and personal health information. And that involves the collecting of that information, the using of that information, and the disclosing of that information. And in today's world and in the area of organ transplants, that certainly involves a computer-system database that houses the information collected. And people access it, which means they're using it, and people obtain it, which means it's being disclosed. As I understand the system now, we have a national system run by the blood services agencies Act. And that registry, we understand, is currently dealt with in Saskatchewan by an agreement that deals with the sharing of information. Again, as we narrow down into the issues that we're interested in, we're interested in the information-sharing aspects of the issue that is in front of you, and again, that involves collecting, using, and disclosing information.

In developing an information-sharing agreement, parties should think about a number of things, and then at some point those things should be translated into a written document. I'm going to ask Diane at this time to list a number of things that parties need to think about very carefully as they get into the information-sharing business, so to speak. Diane?

Ms. Aldridge: — Thanks, Ron. In terms of information-sharing agreements, these are not new to our office. You can imagine all the different information sharing that goes on in the province and elsewhere. And so it's really important when it comes to these agreements that first and foremost they be in writing. Writing is all about making sure that everyone involved knows who's responsible for what those obligations are, and so if there are particular elements that can always be included within these agreements, then there is less likely going to be a misstep. And it's looking at the life cycle of the information too, from collection all the way to destruction, so that there's a less likelihood that that information will end up in the wrong hands, either through inadvertent mistakes or by employees snooping.

So some of the particular elements that we look for is even clarifying what the data elements are. You know, are you dealing with personal information? Are you dealing with personal health information? What's the purpose for the sharing and that you're keeping the parties to those purposes and they're not using it for other things that are unrelated. But also, what's that authority for sharing the information in the first place? If both parties don't have that legal authority or consent, then the information sharing shouldn't happen in the first place. How is it safeguarded? Who will be responsible if there's a privacy breach for looking into that, investigating and taking action at the end of it, providing notification to affected individuals and even looking at what are causes for termination of that agreement. And so it's having that complete picture structured in writing so there are no questions going forward. Ron?

Mr. Kruzeniski: — In our submission, and Diane is the main author of this document, we've listed about 14 items that people should think about. And getting more specific, section 16 of *The Human Tissue Gift Act* — this Act has not been proclaimed; it was passed in about 1915 — deals with the releasing of information from one human tissue organization to another. And I believe and I submit and I request of this committee when you're making recommendations, that one of them be that we recommend an amendment to section 16 to

require information-sharing agreements when human tissue organizations share information.

And what type of things should the legislation refer to? Well it's sort the things that Diane referred to, but more specifically it's on page 2 of our submission and it goes from (a) to (g). And I'm just going to touch on a few of them. That information-sharing agreement should require that there be a description of the purpose: why are you collecting, why are you using, why are you disclosing information?

Number (b), there should be provisions requiring the safeguarding of the information. If a party receives information, our position is they're obligated then to protect that information.

And number (c), prohibiting collecting, using, or disclosing information beyond the purpose that's stated. And that's the reason why you want the purpose; you can only collect for that purpose.

Requiring compliance with the Saskatchewan legislation, we have three pieces of legislation in the province. We have the freedom of information Act, the local authorities freedom of information Act, and *The Health Information Protection Act*. Well if you're receiving that information, it's pretty basic that you ought to comply with our legislation.

Now because organ registries and transfers has a federal aspect to it, there is also federal legislation. But I think we in Saskatchewan should always insist that a body receiving this type of information comply with whatever happens to be the highest standard at the time, whether it's federal legislation or provincial legislation.

Diane mentioned it. There needs to be provisions for terminating the agreement. If the receiving organization doesn't quite live up to what it agreed to, then it should be clear that the arrangement can be terminated. And if it is terminated, there should be a prohibition regarding further collection, use, or disclosure, and then continuing obligation. As long as that receiving organization has the information in its possession, it has an obligation to keep protecting it even though the contract is over.

Down to (f), requiring notice if some of the conditions of the agreement have been broken. And the best example is that if an employee in the receiving organization snoops, that should get reported. That is a breach and inappropriate and the sending organization ought to know. There should also be a clause that allows the sending organization to inspect or do audits. They need to make sure that the receiving organization has in fact, you know, done what it said it's going to do.

So those are the type of things that I'm asking this committee to think about and when you get to doing a report, considering making recommendations on. And we don't just make these recommendations today to you. We have made similar recommendations when it comes to hubs, you know, community initiatives to share information. We've made the recommendations when it comes to researchers under the archives Act, similar suggestions under *The Cancer Agency Act*, and also *The Child and Family Services Act*. We've also made

some proposals to amend *The Health Information Protection Act* and pretty well put in a similar type of proposal.

So it's really a theme or a thrust that we have been talking to all the organizations that hold extremely important and sensitive information, and that is the requirement of an information-sharing agreement. So I do request of this committee, as you make your recommendations and determine the options that our province ought to go ahead with, that you recommend that section 16 be amended to be a bit more robust and have a little more detail and require organizations receiving personal health information to enter into an information-sharing agreement.

On a slightly different topic, in June of this year in our annual report we made proposals to amend *The Health Information Protection Act*, and in particular we made a proposal to amend section 27(4). And really, what this allows is a trustee without consent the authority to convey the wishes of a deceased person when they have indicated they wish to make an organ donation. I think it is important that trustees, after death and where wishes are clearly known, need to communicate — and obviously communicate quickly — regarding the donor and the current situation. So it would assist us, and I hope assist the work that you're doing, if in your report you could recommend that this particular proposal of ours be implemented by the Legislative Assembly.

And finally on another point, and right at the end of our written submission, when I make an organ donation, or anyone else, I think I and my family need to be kept up to date as changes occur. And you know, I may make a donation today and two years from now a policy changes by a health region or by the legislature or whomever. And I think people need to know this, and particularly when someone passes away and the family is grieving and they know there's been an expression of a wish for an organ donation, and then the rules have changed. So what we're requesting is that you recommend to the powers that be, the people that will administer this, that they have kind of a continuous communications plan and that probably means a website that has the latest and the best information as to what Saskatchewan's position and policies are regarding organ donations.

So in closing, I thank you very much for the invitation, for listening to Diane and I. And we commend you on difficult, challenging, but important work, and we'd be most pleased to answer any questions on access to information or protection of people's personal information. Thank you.

The Chair: — Thank you, Mr. Kruzeniski. Committee members, for questions we have Ms. Chartier up.

Ms. Chartier: — Thank you very much for your presentation today. Forgive my ignorance here. I don't have the bill that was passed in 2015 in front of me and it's been a little bit since I looked at it. You've given us the amendment here, but how different . . . You had said you wanted something more detailed and robust to protect people's privacy. But because we don't have the side-by-side bills to compare, I'm just wondering how different this section 16 reads from previous.

Mr. Kruzeniski: — Well I'm going to ask Ms. Aldridge to read

out the section. I think our proposal would really involve adding on words at the end of what's there. But, Ms. Aldridge.

Ms. Aldridge: — That's exactly it. When you look at 16 as it was proposed, it is the whole paragraph, and all that we've added is the clauses underneath. So that's the new part. In addition was "provided the parties enter into a written agreement containing the following elements." So the only additions that we have is that statement at the end of the paragraph and clauses (a) through (h).

Ms. Chartier: — Thank you for that.

Ms. Aldridge: — You're welcome.

Ms. Chartier: — Did you consult or provide, when this original bill . . . When the bill was drafted and before us in 2015, did your office provide some consultation or feedback on it at that point?

Mr. Kruzeniski: — Let me check with Ms. Aldridge, but I . . .

Ms. Aldridge: — No.

Mr. Kruzeniski: — Neither of us recall that we provided input.

Ms. Chartier: — Okay, thank you. Well thank you for that. All right. Well thank you.

Ms. Aldridge: — Can I just add something on that? Generally with our office, we offer this consultation service where any organization, whether it be a public body, a trustee, a health information trustee, or other comes to us and they want feedback on a policy, procedure, a bill, what have you, they provide it to us in advance and then we review it, we give the feedback. We usually do that, have a back-and-forth discussion and, you know, if there's some sort of a formal response that we provide . . . It's a very formalized process.

In this particular case, I don't believe that we actually received anything in advance to provide comment on. And so other than the bill just moving its way through the House, that would have been the only way that it would have been brought to our attention.

Ms. Chartier: — And can I ask once the bill is brought to your attention, so you know there's a bill before the House, do you weigh in at that point? Would you have had communication with the ministry expressing your concerns that it needed to be a little bit more robust?

Mr. Kruzeniski: — Our preference is that the process start early on.

Ms. Chartier: — Yes.

Mr. Kruzeniski: — You know, when the side-by-sides are being worked on or whatever. We have, between Ms. Aldridge and I, tried to comb through the bills and see if there's a clause that jumps out to us that has some access or privacy implications. My concern about that stage is that, you know, it is already tabled in the House. It's gotten first reading, and it's always a little bit harder to get House amendments than to work

on them earlier. So I certainly, you know, would ask all members here, wherever you see it and if you think of it, say, have you consulted our office in advance? We really appreciate people asking that question.

Ms. Chartier: — Thank you.

The Chair: — Ms. Rancourt.

Ms. Rancourt: — I also want to thank you for your presentation. It's really good information here. I do have a question. One of the options that have been kind of discussed to the committee and to myself by other members was that maybe having a process to register for organ donation through another agency might be an option, but I'm wondering what kind of conflict this might have with your personal health information Act.

For example, one of the agencies that was discussed with myself was someone saying maybe we could add it as one of the questions when you go and register for your licence. Are you interested in being an organ donor? And so I guess my question to you guys, because this is your field: what kind of implications would that have with regards to your personal health information Act?

Mr. Kruzeniski: — Well I'm going to say it certainly would depend on which agency . . . You cited the example of the licence issuer. Certainly if that responsibility or authority was given to the licence issuer — I'm assuming it would be by statute or whatever — we'd probably be saying some of the same things we've said to you. It would need to be tied up in an information-sharing contract, and it would need some additional training for the licence issuers.

At the moment, the licence issuers get some personal information about you, you know, your birth date, your address, that sort of thing. They're really starting to get more personal, more sensitive information about you, and I think as the information becomes more sensitive, the training and the standards and the rigour regarding all those employees just increases. If you'd look at licence issuers in this province now, they're all over the province and each of those agencies would have employees that come and go and come and go. So training becomes a continuous thing.

So I think there's some preliminary thoughts on there. If the committee were ever going in that direction, I think I would want to, you know, reflect on it more and make sure the legislation ties up those agencies in a way that they're bound by all the access and privacy legislation in the province.

Ms. Aldridge: — Okay, can I just add something to that? So in terms of the information sharing too, usually it starts with, what's the mandate of the organization? And you know, purposes flow from there in terms of what kind of data collection that the agency can do. And so every time you introduce a new player, you're increasing the risk. And in terms of what Ron said, there's that many more employees and individuals that now have access to that information. And the training piece does become that much more critical. And even in terms of their particular licence, the brokers that are out there . . . We've now had, what is it, three cases of particular privacy

breach investigations that we've been dealing with. So there's always that element in terms of, what safeguards and controls are in place to help prevent or to reduce the likelihood of there being a privacy breach?

Ms. Rancourt: — Thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you. Just with respect to your recommendation for *The Health Information Protection Act*, so obviously our goal or our job here is to try to improve organ donation rates here in Saskatchewan. So again, forgive my ignorance here, but for the recommendation for 27(4)(e), "if the subject individual is deceased . . ." So this again, we're just learning about organ donation here, but obviously some of that communication that happens prior to donation . . . The person might not yet be deceased. They may be, for all intents and purposes, they're still on life support. So how, again from a lawyer's perspective, that word "deceased," so how does that . . . I can see perhaps people who work in organ donation being concerned with that particular element.

Mr. Kruzeniski: — So, Ms. Chartier, what I think I hear you saying is that maybe this is too narrow. And so let me answer it first as . . . This committee, as I understand it, is looking at, you know, trying to increase the number of organ donations. So I think I, thinking about an organ donation, now have to say, well how smoothly does the system work? And therefore when it comes to end of life and I die, I hope my doctor has the ability to communicate with whoever to pass on the information. So that would be the motivation for us putting this in here, is that it wasn't in the existing Act and it should be in this one.

And if you're taking it a step further and saying, well if somebody is on life support and the communication should start then, I think you make a very good point. Certainly on the spur of the moment I can't think of how we would necessarily change this. But if your committee thought this should be slightly broader, I mean I would expect the Ministry of Health and others would take that into account when we get back to doing the amendments to the legislation.

And the only thing about your question that probably, as my brain is scrambling, is how you would say, if someone is on life support, you know, like what descriptive words would you put in there that would authorize the physician to start sharing? You know, does the person have to be dying tomorrow, or what if they're dying 10 days from now? When is the right time? But we could leave some of that up to the legal drafters to figure out.

Ms. Aldridge: — And I could just add a couple of other things. HIPA focuses, or *The Health Information Protection Act* focuses on the living, even though personal health information, it doesn't matter if the individual is alive or deceased. And so when you look at the specific rules around use and disclosure, they focus more so on the living person. And either you can get the express consent of the individual or you could have relied on implied or even deemed or no consent. But that's more so around diagnosis, treatment, or care; if the individual is deceased, obviously they don't need diagnosis, treatment, or care anymore. You know, that time has passed.

And so the wording of the Act doesn't specifically focus on the deceased, and the deceased individual's rights, and when is it appropriate to use or disclose that information. So this particular wording is to fill a gap in terms of, in this particular case, even to get the ball rolling to see if the individual did or didn't express consent, or that maybe the family even needs to have a discussion with to find out what their intentions are. This would give the authority to move in that direction.

Ms. Chartier: — Okay, thank you. So there's latitude then, I think what I'm asking is if there's latitude if the person's . . . in HIPA [*The Health Information Protection Act*] then, if the person's not yet deceased to be able to . . . I guess the information-sharing piece is the challenge here. So is there latitude to be able to begin those conversations if someone is gravely ill or at the end, if death is imminent? Is there latitude within HIPA before the person is deceased? Because those conversations do . . . Time is really of the essence when it comes to transplants.

Mr. Kruzeniski: — Well I'm going to give you kind of a typical lawyer answer: yes and no. The no part is that, based on 27(4), you don't need consent. If the person has died, you don't need consent. You can communicate.

If the person is alive, you can't really communicate unless you do obtain consent. Now there's a couple of ways you can get consent. If I'm in my hospital bed and I'm conscious and competent, I can consent. If I was unconscious, my proxy under the health care directive, commonly called an advanced care directive, could consent. Or my attorney, under a personal power of attorney, could consent. So there would be some ability if a representative would consent on my behalf if I'm unconscious or incapable.

But I think your question, you know, needs a bit more study in the sense of, should our proposed amendment have been a slightly bit broader, contemplating end of life and that sort of thing. I may toss that one on Ms. Aldridge's desk to think about more.

Ms. Chartier: — And I think that would be a great conversation to have with the organ donation body here, the program in Saskatoon. I think that would be a great place to have that conversation.

But I also just want to comment. I appreciate the last part of your presentation where you talk about ongoing communication and education. We heard that from our last witness as well, in a different context obviously. But I think that that is probably one big part or a key to this — whether it's physicians communicating with patients, whether it's families communicating with their family members, and government and organizations responsible for organ donation continuing to communicate with citizens in the province. So I really appreciate that you added that because I think that that's a key part of that. So thank you very much. And thanks for your time today.

The Chair: — Are there any other questions? Mr. Buckingham.

Mr. Buckingham: — Thank you very much for your submissions. I just have a question on section 27. If that were to

become law as presented, and I were to have it in my will that I am an organ donor or I wish to be an organ donor but I haven't signed my organ donor card, would I still be deemed to be an organ donor? And I guess the second part to that, with or without family involvement or if family were to disagree, would it still be binding that it's in my will that I want to donate my organs, that it would be binding that I would be . . .

Mr. Kruzeniski: — You are really getting into an area where maybe more legal research is required, and you may be beyond my years of experience. Looking at the proposal we gave, it did say "wishes," so it would authorize the trustee to express my wishes wherever my wishes might be — in my will, in another document, or in an organ donor card. What I don't know offhand and I don't know if Ms. Aldridge knows is, is it only the organ donation card that authorizes the donation. I'm not just sure but I would, you know, after this session I would rush to the human tissues donation Act and take a look at the definitions and see just what authorizes the donation.

[14:15]

Ms. Aldridge: — And part of what we do too is when we get these specific questions, of course we start with the legislation and what kind of latitude is there with the specific provision. Then we have to look at what the other laws say. So without even getting into the specifics and knowing the consent and what's required under HIPA, I'd also have to take a look to see Part III — consent by persons for use of body after death, replication of consent — do a little cross reference there, but also then to look at the dates, what the specific language was, what the protocols are that are in place, and then seeing if there's that alignment across the board.

So there would be a number of different steps we would need to get to before we would offer that kind of a specific summary advice. Often too that's provided to us in advance and then we could spend the time going through, you know, the particular circumstances to have more . . . and I'm not going to say definitive answer because we don't do what we call give advance rulings, because that's not our role.

Mr. Kruzeniski: — I would make this offer to the committee, and I don't know how it exactly works, but as you deliberate and after you hear all your consultations, if you have one or two or three questions of the access and privacy nature — through your Chair or through Mr. Park you communicate to them — we'd certainly provide you with written answers. And as Ms. Aldridge said, maybe we'll be definitive and occasionally we wouldn't be definitive.

The Chair: — Well thank you very much for your submissions. Are there any other questions? Okay. Before we shut down, I want to table HUS 12-28, Saskatchewan Information and Privacy Commissioner: Submission regarding organ donations, dated September 6, 2016. I want to thank Mr. Kruzeniski and Ms. Aldridge for your submission today. And, Ms. Chartier, you . . .

Ms. Chartier: — I have one more question, sorry.

The Chair: — Okay, go ahead. Yes, for sure.

Ms. Chartier: — While we have you here, and just being a little proactive . . . And we're early days here in our witnesses, but there has been talk of opt-out programs. So I'm just wondering, so you're deemed to be a donor unless you opt out. I'm just wondering, sort of rough or broad strokes here, what your office or what your perspective would be on an opt-out program? Are there privacy concerns around that?

Mr. Kruzeniski: — Opt-in/opt-out is, I think, issues that, you know, I really respect that this committee has to deal with. And I think to some extent it is beyond our expertise because it involves significant policy positions that the province has to take.

My thinking of it is whatever option is chosen, there are privacy implications. If you have a system where I opt in, you have to register my opting in. If you have a system where I opt out, you have to register my opting out. So however you cut it, somewhere there's a computer system that has some very sensitive information about me, whether I'm a contributing citizen and giving my organs or I'm on the other, the opting-out-part citizen who says there's no way you can take my organs. So the privacy concerns are the same — extremely sensitive information. The rest I have to leave to this committee to sort out as to what is the best option for our province.

Ms. Chartier: — And then we can ask you, you've given us the open door to ask you, if we come to some ideas here, we can bring those to you for your input. Thank you for that.

Mr. Kruzeniski: — I'd be most pleased.

Ms. Chartier: — Okay.

The Chair: — Well thank you very much again. We will resume our public hearings tomorrow at 9 a.m. I would now ask for a motion to adjourn. Mr. Buckingham.

This committee stands adjourned until Wednesday, September 7th, 2016, at 9 a.m. Thank you very much.

[The committee adjourned at 14:20.]