STANDING COMMITTEE ON HUMAN SERVICES

Hansard Verbatim Report

No. 12 – September 7, 2016

Legislative Assembly of Saskatchewan

Twenty-Eighth Legislature

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

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

Public Hearings: Improving Organ and Tissue Donation Rates in Saskatchewan

[The committee met at 08:59.]

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

We will continue with our public hearings on organ and tissue donation rights in Saskatchewan. Our presenter this morning is Mr. Cory Furman. Welcome to the committee today, sir. I would like you to introduce yourself and anyone that may be presenting with you. Please state your name and position within the organization represented.

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. Electronic copies of 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 question and recognize each member that is to speak. Members are not permitted to engage the witness 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, sir, if you'd please proceed with your presentation.

Presenter: Cory Furman

Mr. Furman: — Thank you, Mr. Chair. My name is Cory Furman and this is my wife, Tammy Furman. We are just here representing ourselves today to speak on this issue which is of great personal importance to us. I want to thank the committee for your time this morning and for making some time to engage in some discussion and to hear what we have to say. I know that you got started yesterday already and you probably heard some stories already, some touching stories of people whose lives have been changed by organ donation. I thought what better way to start than, you know, being a little nervous, I thought what better way to start than with a joke.

So I did a little Google search and apparently at the Edinburgh Fringe Festival this year the number one joke that was voted the best joke made by a comedian at a comedy festival is an organ donation joke, believe it or not. And it's very simple. The comedian stands up and says, so my dad's trying to get me to sign my organ donor card. He's a man after my own heart.

So I thought maybe with a little bit of levity I could — and boos in the gallery — I'll get into the substance of our presentation.

From our perspective this is a very important topic, and we're glad to see the legislature from both sides having a look at what we can do to increase organ and tissue donation rates in Saskatchewan because it's a topic that's rooted for us in a story that started in 2010. I don't need to belabour the point of our personal story. But the personal story that made this issue more important to us than just frankly thinking about the organ donation sticker on your driver's licence was we were on a family vacation in Hawaii in 2010. And Tammy actually ended up going into acute liver failure and was put in an induced coma until she could have a . . . she had a liver transplant. Well we went on family vacation to have a liver transplant.

These are a couple of pictures that were taken right after the transplant, which to me are just . . . Again I'm not going to belabour the point, but there's lots of good stories that come from people. People's lives are saved and families are saved from organ donations and transplants. And so we're excited for whatever recommendations that you as a group come up with to help to enhance these types of outcomes in Saskatchewan.

Our proposal to you is simple. I mean, we propose to you today that the committee endorse the move from an opt-in system to a system of presumed consent, an opt-out organ donation framework, in Saskatchewan. I'd love for that to happen in Saskatchewan and for it to kind of be the catalyst for it to happen elsewhere in Canada or in North America. We think that Saskatchewan could be a leader on this. Certainly we have some comment later in our presentation, but I think there are some other half measures the committee could think about or could take. But really having thought about this a fair bit over the last four or five years, it seems to us that this would be the way that we could really contemplate making real change and making a real improvement in this area.

You'll probably hear all the stats from lots of people smarter than us about what the stats look like. I just did a quick little search and, just to frame my own thinking, a Saskatchewan-specific search, and the newest numbers I could find were from 2014. In 2014 in Saskatchewan there were 26 transplants performed. I could have probably parsed it out by individual organ type, but there were 26 organ transplants performed in Saskatchewan. There were 109 people waiting for organ transplants in Saskatchewan that year. Three people died waiting for an organ to become available. Three hundred people died in Canada that year awaiting an organ transplant. So we've got, on the transplant side, I mean certainly we have health care professionals here and health care capacity to do transplants. But on the donation side of the ledger, we did 26 transplants in Saskatchewan but there were only 14 organs donated in Saskatchewan that year.

An interesting item that I noticed in this material and this is . . . I'm happy to send this, Mr. Chair, to the committee staff if you want to look at it. There's a little report on the Canadian Institute of Health Information website that I grabbed these numbers out of, but an interesting, glaring number to me is that of the only 14 organs that were donated in Saskatchewan in 2014, they were all from brain-dead donors. There were no donations from cardiac death donors. Again I'm not sure what the exact terminology is that's used to refer to the donor situation versus, you know, living donors and those types of things.

But obviously drilling back into that is something of interest probably for the committee also. Because if, for example, if cardiac death donations are primarily . . . and I'm guessing at this because I don't know. But if cardiac death donations were, for example, primarily accident victims and those types of things versus brain-death victims being folks that were in the hospital under more intensive medical care, again there's probably something to be learned from that.

In that same 2014 time frame, there are only three referrals of potential donors in the entire province to the organ procurement folks here. So there were only three, and as I understand the definition of that referral term, it's basically where a hospital has identified a potential donor and makes a referral to the organ procurement people in the province to follow up and speak with the family, etc. So long story short, we don't even have enough organs donated in Saskatchewan to fulfill the need of the people of Saskatchewan. We, by those numbers, again my cocktail-napkin math says we were net minus 12 there. We did 12 transplants in Saskatchewan, organs that we got from somewhere else. So I think it would be great for Saskatchewan to, at the very least, be in the position that we had an organ donation pool that would meet our own needs.

This is just a little graph that I made from the numbers in that same report that shows the number of referrals versus the number of donations. There wasn't a single referral in 2013. The number in 2013 was zero. So there was not a single organ donation referral, in the methodology of that report anyways, made in 2013.

So the problem we have is we're not getting enough organs donated to even help people here. I think part of that is we're not identifying enough donors to enhance the donation numbers. And interestingly, and probably a subject of analysis by somebody smarter than us, is that issue of brain-death versus cardiac-death-related donors, at least in those trauma donation cases. There's something to be learned in there as well.

Some of the challenges that I think exist in the environment here in Saskatchewan, which make it difficult for this committee and make it difficult for health care professionals in the community to potentially help with the organ donation, with organ donation statistics without some kind of help in the context or the framework that they're working in, I mean we've got a geographically distributed population which, I mean . . . And again none of these things are going to be surprises to any of you. Especially, you know, we've got members of the committee sitting around the table from all corners of the province, geographically distributed population.

One of the things I think that . . . We've spent a lot of time trying to think about what types of things could we try to advocate for that could help to generate more donation, and I mean beyond the geographic dispersion of the population. I mean, people, whatever corner of the province they're from, they still potentially support organ donation. Geographic distribution and the size of the hospitals in the province is, I think the availability of the more sophisticated medical care that you need to facilitate these types of procedures is an issue that needs to be addressed. You know, we've got a lot of small-town hospitals. They may not all have the necessary, I mean they may not . . . They're for sure not going to have the necessary equipment to facilitate organ transplantation or donation in all those hospitals.

But even beyond that, smaller hospitals, smaller communities, I think there's probably an emotional hurdle frankly. Again I try to look at this from . . . I had a pretty emotional experience in this. Tammy was in a coma so she didn't actually experience a lot of the . . . have the same experience that I did. But I had an interesting experience in that we were in a sophisticated trauma hospital that had, frankly, a complete team of people that did nothing but organ transplants. Honestly, the doctor, the intensivist that was looking after her for six days in the ICU [intensive care unit] while they looked for an organ was actually a specialist who specialized in preparing patients for liver transplants, if you can believe that there is that narrow a specialty.

So I think talking to them, everything was very matter-of-fact, and maybe by virtue of our background — we're both lawyers, and so I think I tend to maybe not be quite so emotional about things. But I have some empathy for the health care folks that are involved in these types of processes, particularly in a smaller community. You're in a smaller hospital in a smaller community; it's not going to be the easiest discussion to have, to go and engage in a discussion with a family who frankly may be friends of your family about . . . And again I think this is beyond just . . . beyond the health care providers. It's an entire cultural thing.

And I think there is a cultural shift and a cultural acceptance of organ donation. But that emotional hurdle, and probably the limited availability of specialist training for health care providers in our geographically distributed health care system, I think is an issue that hopefully we can see from the committee's work and from whatever's done by the government on this, hopefully we can see some help there as well.

I think that the opt-out system, if it were implemented, would provide an easy opening to folks in those types of discussions to maybe more easily engage in the discussion. But those I think are some of the challenges. I think a lot of the opportunities that are available to us though, flipping away from the problems for a minute and looking at sort of what our opportunity matrix looks like, I mean I think there's a lot more opportunity for us to do something like this in Saskatchewan now than probably there ever was before.

Since this happened we've been sort of . . . It's funny. Saskatchewan's a small enough community to come back . . . I mean we were literally out of town with this hospital stuff for probably a couple of months. You get back. Lots of people have kind of heard a snippet of your story. Lori's probably heard this story because she knows my brother-in-law, apparently, from Estevan. But in any event, there's widespread — again my non-scientific poll — there's widespread acceptance for opt-out organ donation policy in Saskatchewan. I was on Gormley yesterday talking about it. There wasn't a single negative call-in.

Everyone that I've talked to, everyone that, I think, that Tammy's talked to . . . I mean I think if we were to go in that direction and are respectful of people's wishes and make it easy for people to opt out should they wish to do so, I think there is widespread . . . Our belief is that there is widespread public acceptance and public appetite for something like this.

So I mean I think that the socialization and the culturalization of the idea of opt-out is there. Because doing a little bit of reading about it over the last couple months preparing for today, a couple of academic pieces that I wrote were saying, you know, look, the one thing that you need to be careful about if you're going to move in the direction of presumed consent is that that idea needs to be socialized first before you just kind of drop the bomb. I think that my own belief is we're there, frankly, I mean that there is some socialization of that idea.

[09:15]

I think the other opportunities that we have that will help and I think help to a degree with that geographical distribution, for example, and honestly, these things could help in something short of presumed consent also, but we have the STARS [Shock Trauma Air Rescue Society] air ambulance available to us now which we never had before.

So I mean in terms of being able to move, whether it's moving the doctor to the donor or moving the donor, frankly probably at the end of the day, my guess is what would end up happening is if there was a move in the direction of, if we all of a sudden had enough organ donation, if we had enough organ material to facilitate a more timely transplant regime, probably at the end of the day the health folks would end up designating whether it's one or two surgical centres. And frankly it may just be one surgical centre, whether it's Saskatoon, Regina, whatever, where they would do this work. And probably what you would do is move the donor and the recipient to the same hospital and you would just do everything there.

In our case, the only thing we know about the donor in Tammy's case is that it was a 17-year-old boy from Seattle. So we don't know much. In that case they moved the organ quite a long ways to do the transplant. But we have the ability now . . . I mean I think we would have had the ability before in maybe less emergent cases, but with that capability, we can move people a little more easily to where we can build the expertise to do the transplants.

And hand in hand with that, I think with the building of a children's hospital coming in Saskatoon and other medical facilities . . . I mean my understanding is that around that children's hospital in particular, there will be or there already is the building of a real cluster of medical expertise that could be useful to folks who need transplants. And I dare say beyond people that need transplants, you can also build the . . . Again I know, drawing back into our own situation, the surgeon who did Tammy's liver transplant was also a cardiac surgeon. Like, talk about a guy with way more brains than I have.

So I think actually by building, frankly by building commercial opportunity for these folks that are going to do this type of work, you can build a good reason for them to build their practice here and for us to enjoy the benefit of that, of a cluster of medical expertise that we may or may not have here now; I don't know. But I suspect by having some work for those guys to do, that might be helpful. So I think that the building of the children's hospital, which will have a medical cluster built around it, the availability of the STARS program, and just the general increasing public awareness around the importance of organ donation, those types of things, those will all be helpful.

Something I learned from a caller on Gormley yesterday, and this is just a little difference from — I just was listening to the show after I talked to John, and I learned this — different from the US [United States] situation. So in the US scenario, we don't know who the donor family was but there is a . . . We've written to them a few times and we can basically send a letter to the hospital and the hospital will forward it on through the . . . So they know who the donors are; we don't. If we ever met them, that would be another emotional story.

But I learned from a woman who phoned in yesterday — and I show my ignorance a little bit of the Canadian system — but my understanding is that there is no similar mechanism here. And that would be a very simple, small recommendation that the committee might consider, would even just be to consider making it . . . Again people may not want to know. It's maybe too emotional to know all the information. But to facilitate the ability to even make that kind of connection, I think, to facilitate the ability to say thank you is very important to . . . I'd like to think it's important to the donor family. I know it was important to us and I think it would also be important culturally as people know that that's an option that would be helpful.

So in terms of implementing an opt-out system, I think what that might look like is the creation of the environment, so to create or change the legislative environment for an opt-out system. Truthfully I'm not sure what that exactly looks like even though Tammy and I are both lawyers. You guys have the army at the Justice department at your beck and call to figure out what that actually looks like. But I think what the implementation of an opt-out system would look like — creating the environment, so creating, changing the legislation, or creating the legislation to create that presumed consent environment — I think to be fair and respectful, it's good to have multiple opt-out . . . Just make it easy. People don't want to . . . If they want to opt out, let's make it easier for them to opt out than it is to opt in right now.

And whether that's through the sticker on your health card, asking the question, there's some thoughts on this in the paper that we'll table, Mr. Chair, has a few more thoughts in there. But you know, asking the question when people do their driver's licence and somehow recording it against that and getting that information across into the electronic health record. And even my understanding is that across government there's some work being done on just a common identity project, which is sort of a centralized identity store for all the information that government has to deal with, with different programs they deliver and things.

Storing that information, capture it, and making lots of ways to capture it, making it stored in a way that people that need to access it can access it, and by capturing that information, there's probably lots of other tie-ons too. Beyond the committee's instant mandate of enhancing donation rates, there's probably then also some work that could be done if you capture all that data. I do lots of . . . I'm a patent lawyer and I do software patent work so I'm always . . . The second thing would be finding ways to use that data to do better matching and to facilitate quicker transplants. Those are other things to look at, but capturing that data, making it easy for people to opt out.

And creating some — and I don't propose to know the answer on this one, but I throw it out there as something to talk about — creating clarity of roles in the legislation for the donors and their families and the medical team. Again I know this from talking to the doctors in Hawaii when they . . . I got a medical degree in a couple of weeks there from . . . I didn't have a lot of other stuff to do than sit around the hospital and talk to the doctors and nurses who humoured me with lots of information. And they told me, and I've learned this subsequently is very similar in Canada that, frankly, if a single member of a donor's family doesn't want the donation to happen, they will not abide by the wishes of the donor and they won't take the donation, because I mean in the US context, they're afraid of getting sued. But I think — and I don't know what the answer to that is — but I think it would be good to have some clarity in role there that if, I mean, if the donor has . . . the donor's wish should prevail. And I mean in the case of an opt-out scenario, if the donor had indicated an opt out, I think we just should observe that just like you would observe their desire to opt in now.

I think creating the environment and capturing all that information would make it easier for medical staff. So for example, by capturing any opt-out information with the presumed consent — or again you could extrapolate a lot of this onto the existing system also — but by capturing that information, you make it a lot easier for medical staff. For example, first responders at the scene of an accident of, you know, of a cardiac death for example, may have easier access to information about somebody's donor status. And they can be making the hospital aware of what's going on. I think information flow is a big piece of this, and so it will make it easier for medical staff to facilitate donations and transplants. I think it also makes, having that information at hand also makes it easier to provide better availability of support services for donors and their families.

I think one of the things, my impression is that one of the things they did in the States well, and I mean I think probably we do this here but obviously — well in 2013 we didn't do it very much when there were zero referrals — but the way they generate . . . From what I've read is, the key is to talk to people as quickly as possible. And I know that in the US environment from talking to the people on the transplant team there, I mean frankly they literally monitor the patient lists in the hospitals to identify potential donor families as quickly as they can. And again capturing as much information as they can as quickly as possible is very helpful.

All of this is all well and good, but I think we also then just need to keep in mind that we need to provide the necessary training and support for health care providers in Saskatchewan here too. One of the things I think that could be provided in an opt-out system or otherwise would be to provide some kind of, whether it's training or even provide some on-call resource, for example, for rural health care providers in the province in those small hospitals, whether it's a call centre, whether it's some training, whether it's frankly, we have a patient in our hospital who is a likely donor, would you come out and talk to the family — those kinds of things.

I think some support there regardless of whether we have opt-out or opt-in . . . I'm trying to throw you lots of options here that you could even look at to enhance the current system. But what we really want to see is this move towards presumed consent. But I think that regardless of whether it's presumed consent, the health care providers need help. I think that, downstream, if we implement the opt-out system, I think one of the greatest benefits to us downstream is we can develop more local medical expertise that's useful for this reason and otherwise. I think there's increased organ availability, decrease in transplant wait times if we've got more organs available to us, which I think also probably results in better recovery times and better outcomes for the recipient of the transplant because they're not waiting as long.

Enhancement of the locally available medical expertise. Honestly there's going to be cost savings for people not waiting as long which could be redeployed into saving more lives. I mean, honestly, I'm probably lucky that I don't know anybody personally who has to do kidney dialysis. But lookit, with kidneys for example, if we could decrease the length of time that somebody had to do dialysis by enhancing the availability of kidneys for transplants, that would be an amazing thing. There'd be an occasional opportunity, I think, for us to help patients outside the province, and I think there's actually an opportunity for Saskatchewan to be seen as a leader in this area.

I've got a little bit of something humorous to show you here. I've got a little video to show you here at the end. Have you got anything else, Tam? So then, Mr. Chair, I'll just show you this little two-minute video. I wanted to start with a joke and end with something that I think is touching but kind of funny, and then we're happy to stay and answer as many questions as the committee might have.

[Video presentation.]

[09:30]

Mr. Furman: — That video apparently won an award for some ad agency for being . . . Like they entered it in a contest and a friend of mine who's in the advertising business sent it to me one day. I always want to get up and clap or I have a little tear in the corner of my eye every time I watch it. But subject to other questions of the committee, Mr. Chair, that's our submission.

The Chair: — Okay. We have Ms. Carr already on the list wanting to ask some questions.

Ms. Carr: — Thank you. Well thank you so much for joining us today and sharing your story. It sounds to me like someone was watching out for you and you were in the right place at the right time because you got great care and you're here with us today.

This is a very interesting concept. You know, I've heard people talk about it and I'm very intrigued by it. So you talk about the informal surveys that you've taken and you feel people are prepared for the opt-out version right now. So if something were to take place, there'd have to be a great deal of consultation and public awareness that happens to ensure that it's accepted and not shot down once, you know, something like this happens. How do you see that happening so that it's the most successful it can be? Have you thought about that part of it?

Ms. Furman: — Well one of the things that I think is important is sharing stories, right, sharing stories so people understand what an organ donation can mean to someone's life. And that's one of the reasons that we're here today. Because frankly, before this happened to me I didn't really think too much about it, and I think there's probably a number of people who are in a similar circumstance. And I had no clue that you could get an organ from, you know, a generous donation and then basically resume your life and do everything that you had been doing before. And I don't know if people, you know, realize that, if they understand what a benefit they are giving to you because they essentially do give you your life back.

So I think that's one way of kind of getting people to accept that this is a good thing to do and that the negative consequences of that are . . . I can't even imagine what a negative consequence would be of being an organ donor.

Ms. Carr: — Okay, thank you.

Mr. Furman: — Probably to sort of just tack on to Tammy's thought there, I think that in my mind if you were, again, in socializing a move in that direction, I think a big part of it would probably be telling those stories and building, and I think culturally people are already accepting of it, but telling those stories and sort of showing people how important and just how important it can be for that to happen for someone who . . . You know, and the flip side of it is, it's a gift you can give. You don't need your organs anymore really, if you're headed in that direction.

Again I find myself, when I get a little misty eyed about this kind of stuff, I find myself occasionally reverting to humour. And I found a little picture that somebody sent me on Facebook the other day. They said, of course I'm an organ donor; who wouldn't want a piece of this?

But humour aside, I think telling those stories, I'd like to think that the public discourse and dialogue around it would not be, you know, offensive or too heated. I mean because again I really think an important part of the opt-out system is just make it easy for . . . Someone who's uncomfortable with it doesn't have to participate. So I think that's probably some of the messaging. I don't know procedurally what it would look like, but that's what some of the messaging in my mind I think would look like.

Ms. Furman: — Yes, just to add to that too, I think that it is important to really get out the message that you're not being forced to do anything you don't want to do, that you can say no.

Ms. Carr: — Thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Well first of all, thank you so much, Tammy and Cory, for sharing your experience and your thoughts. I think I've got lots of questions but I know there'll be some back and forth. So I just wanted to start with, there are no other Canadian jurisdictions right now that do opt-out?

Mr. Furman: — If I'm not mistaken, I read that I think it's New Brunswick was talking about it. New Brunswick or Nova Scotia was talking about it. I have a friend who works in government down there and I was actually going to just call him one day and ask him if they ever did anything about it. I'm not sure what the status of it is. There was some talk about it I believe in one of those jurisdictions.

Ms. Chartier: — In your own experience and having lived your experience — and obviously you've done some research looking at CIHI [Canadian Institute of Health Information] numbers, things like that — have you looked at other jurisdictions that do opt-out like outside of Canada, what they're doing and how they're making that easy for people?

Mr. Furman: — You know, opt-out is not widely done yet. I believe it's Finland. There's a couple of Scandinavian countries that do it. Interestingly enough there was a *Globe and Mail* article a couple of years ago that showed that the actual, the country that had the highest per million . . . They measured donation rates and in Canada there were 15 donations per million people. In the US it was 26. In Tammy's case, for example, I mean the liver that she was transplanted with was apparently the fourth one that they found that matched the profile but they kept waiting to find frankly a better one. But so 26 was the number in the US, but what I found really interesting was the number in Spain I think was 32.

So I just kind of assumed when I learned about the American system that maybe the donation rates, and if you really wanted to get socio-economic and drill into it in some way, may be attributable to the for-profit versus social medicare situation. I don't have answers to those questions, but I thought it was interesting to think about, that the numbers were highest in Spain. And I believe there is opt-out in the . . . I'll have a look at that and I'd be happy to send it to the Chair if I can find it for you guys to have a look at it, but I believe it's Finland or Scandinavia where there's one jurisdiction that's done it quite effectively.

Ms. Chartier: — Okay. I think I have some more questions but I'll pass it on. But I would actually have a request of the committee, of our Clerk and the staff. Would it be possible to have a literature search done on opt-out provisions in order to help us, once we're done all our presentations, to have a little bit more information to better equip our deliberations? Would that be a possibility? Do I need to make a motion?

The Chair: — No, no.

Ms. Chartier: — Or do I just make that request? Okay, if we could have a literature search on background in terms of opt-out in other jurisdictions, what they're doing, that would be very helpful. I hate to give you more work to do, but thank you.

The Chair: — Mr. Parent.

Mr. Parent: — She asked the question that I was going to ask: anywhere else it was utilized, the opt-out in like Europe or anywhere like that.

The Chair: — Ms. Carr, did you have another question?

Ms. Carr: — No, but I did a quick Google search and I have three countries that do it successfully right now — Spain, Austria, and Belgium. And they have opt-out systems and high donor rates.

The Chair: — Okay. Thank you for that. Back to Ms. Chartier.

Ms. Chartier: — Thank you. I know one of the things . . . Obviously we don't have opt-out here in Canada yet — maybe the discussion in Nova Scotia — but there are other provinces who are doing a better job than us, so some of the things that they're doing. Your point no. 3 under opportunity, when you talk about "enhancing health worker training to equip care providers with the tools to proactively identify and respectfully solicit donations within the current . . . [system]," I know one thing that I've heard in my discussions with health care professionals within the transplant program, one piece that's missing is for the average doctor, whether it's in a smaller community or in one of the larger centres, knowing who makes a good donor. And we actually heard that yesterday as well. I think even medical professionals don't always understand that piece.

But the second piece is around having the ability to have those respectful conversations. And I know in Ontario they use something called donor physicians who work with their colleagues to better spread the word and help equip their colleagues with the tools they need to make the ask and to identify donors and look at missed opportunities. I'm wondering if you've looked into the idea of donor physicians at all.

Mr. Furman: — I haven't looked into it although I did understand from, again from our experience in the States for . . . And again it's kind of different because they're bigger hospitals and larger programs. But I did understand that the way that the program worked there, sort of the OPOs, they call them, the organ procurement organizations, so the transplant team that were involved in . . . Any support, frankly, we can provide for these people is a good thing because I tell you, like those women to this day are like my sisters. I talk to them about every six months on the phone. They were fantastic.

One of them in particular, she had worked for 25 years in organ transplant. For a number of years prior to that she had been working with recipients, but she worked prior to that for 15-plus years with working with donor families. And she actually said that was her favourite thing to do. As I understood it from her, to your point, maybe not so much donor physicians, but she was a nurse and had lots of experience and training. And their job really was to sort of monitor and have the discussion. So whether it was a physician or whether it would be easier to create like some other kind of a non-physician support, I think it would all be good because to provide the ability for, just to provide the ability to have those discussions for . . . Again I like to think at least that I get it from the perspective of the emotional hurdle there could be for the caregiver. Or even if it's not an emotional hurdle, it's just a training issue. So the donor physician thing I think would be a good idea, or alternatively putting a little more resource into that, just into that whole organ procurement side of the cycle such that whether it's just training with the existing resources or adding some resources, I think would be helpful.

Ms. Chartier: — Thank you for that.

The Chair: — Go ahead. One more and then Mr. Michelson.

Ms. Chartier: — Oh no, you go ahead.

The Chair: — Mr. Michelson.

Mr. Michelson: — Yes, thank you, Mr. Chair. Thank you for the presentation. And it was very informing and I appreciate the amount of research you've done and the suggestions you've made. You did touch on in the American model that they would . . . Like you don't know; you never were in touch with the person that made the donation. All you know, it was from a teenage male. I guess part of our research, and part of what we have to gain in understanding is, how does that family feel? Because I can't imagine if my son turned 17, got in a car accident, had signed his donor card, and you know, his organs were harvested and we found out after. Yes, it was his wishes, but there's a lot of emotion around that. And again I don't know how that is handled. But I would think that would be part of the consideration, and obviously you've gone through a lot of those emotions as well.

Mr. Furman: — Well I think you make a good point. I mean, and frankly, I would love nothing more than to comfort the donor family, and frankly know how they feel and give them a big hug, to be honest with you. An anecdotal thing: this was an interesting thing to me as I have a friend . . . This was around the time when Tammy was just recovering from the surgery. And I have a friend in the States whose son had passed away and he was quite young. He was 13 years old or something like that, and they had donated his organs. And he just phoned me to see how things were going.

He actually told me, which I found a little bit alarming, that they had donated all their son's organs and not a single person had said thank you. And so that moved me a lot. I mean I already was overflowing with emotion and gratitude for this donor family. But I mean the donors, I don't know how they feel. I imagine . . . I mean it's going to be obvious they probably don't necessarily want to have a family picnic with you or anything. But I'd like to think that if you made an organ donation you could find, at some point in your own grieving process, some comfort in the fact that you've saved a lot of lives.

I agree with you though that that's something particularly . . . like for example, a donor who's not of the age of majority, those kinds of things. That would all be kind of stuff you'd have to think about in . . . Truthfully that's probably a carve-out to straight opt-out, but again I don't know what that would look like.

But I think that people should have the comfort that we're not creating some kind of a Monty Python sketch where, you know, there's a Mr. Death at the door for you and they're here for your organs. I think that if people have comfort that those types of things have been reflected in the deliberation around the process and that the framework that's established is respectful, I still believe that people would be openly accepting of the opt-out.

[09:45]

Ms. Furman: — I was just going to add to your question that I think that if someone isn't of the age of majority, there obviously has to be a provision built into any legislation that's done in this regard to specifically reflect what the situation is for a minor and whether that, you know, that the parent has control over the opt-in or opt-out for that child. I think that's an important thing that has to be analyzed.

Mr. Michelson: — The spectrum of emotions is such a universe in itself. And I'm like you — I would be forever grateful. And yet there may be people on the other side that don't want to be reminded of that accident or that event or whatever. So yes, it would be a very delicate balance.

Mr. Furman: — I think frankly that's okay too. I mean I actually think that the system and I think people . . . A recipient of an organ frankly can and should be respectful of that also. I mean I don't think that anybody . . . I don't ever want to meet the donor family that donated the liver that saved Tammy's life if they don't want to be reminded or they don't want to meet me. I still catch myself about every year and a half or two years writing them a letter and sending it to the hospital in Hawaii to forward it on. I never hear anything back. I don't expect to hear anything back, but if they ever did want to reach out, it would be fine. But you're right. I think that the whole process needs to be . . . While I think that the opt-out system gives us the ability to potentially save a lot of lives, I do think that the process needs to be very respectful of the emotion that the donor families are going to be going through.

So I can't imagine the emotion of that fellow in Saskatoon, that car accident and that family where he donated all the organs. I can't imagine the emotion. But again, long story short, I think that the process can be respectful of that, and I think that the committee in their deliberations should be respectful of that in terms of what you might reflect in a recommendation that certainly we need to be cognizant of the fact that it's a pretty emotionally charged situation all round, and there can be positive outcomes for everyone, but we need to respect sort of the emotional needs of the donors as much as the recipients.

Mr. Michelson: — There's certainly a lot to this, though. Even the ultimate goal is if we can even double the amount of donors, we'll come a long way. And that's still a very small percentage. So thank you again. Thank you, Mr. Chair.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thanks. Just one more. I was wondering. Obviously this turnaround happened very quickly for you. Maybe it was a good thing that it happened in the States. It was a four-day wait that you ended up having . . . Like from the time you ended up in the hospital to actually getting the transplant, how much of a wait was it?

Mr. Furman: — Tammy went into the hospital on a Saturday night. It was that long weekend. What is that long weekend they have in the States in February? It was February. We were in Hawaii in the winter. It's Presidents' Day or something. So the long weekend, the matching registry was closed so they couldn't do an organ . . . The day after she went in the hospital, there's something very bizarre and the whole experience left me with a whole new layer of empathy for anyone that has sort of significant medical trauma in their family. But sitting down with the hepatologist the day after, I mean she was already in a coma in the hospital because they were worried about brain damage and this and that. Sitting down with the hepatologist and him telling me she needs a transplant — her liver is dead — when we'd been on vacation for two weeks, is a weird thing.

So that was Saturday. So they did all these tests and stuff. Tuesday morning when the matching registry or whatever opened up, they were ready to kind of do a match. It was Thursday afternoon when they came and told me they had found a liver. And then Friday night, late, was when . . . Saturday morning was when they did the transplant. So from the time they sort of submitted the matching information to the time they found a donor was two or three days.

Now the way the system, and I think the system, I think the matching system works very similar in Canada, but there's this sort of, I think it's 1-to-40 scale, and you are placed on this scale as to the severity of your need for the organ. The higher the number, the lower your priority. And then there's a right-now category that goes over top of the 1, and depending on what code you are, or what level you're at in there, the size of the donor pool increases. So if you are below 25 you are limited to a state-only donor pool. So in Hawaii, which is on a rock in the middle of the ocean, and there's a big aboriginal culture and not a lot of donation there, it would have been a real problem. Now in Tammy's case, she was in the right-now category, so really any matching liver that was in the entire US was available to them to take so long as it was within a plane flight away.

But it was the process of the match and then it was about a week from the time she went in the hospital to the time the surgery was done, and then another . . . We were there for another two or three weeks of recovery/rehab and then spent about another month or more in Edmonton when we came back to Canada.

Ms. Chartier: — I guess my question is, had you been here — so you gave us 2014 stats, although you didn't parse out the different kinds of transplants — do you have any sense of how long it could have been? Have you met with other people who've had similar experiences, or do you have any sense of how long you would have waited here?

Mr. Furman: — It's interesting, because on return . . . I mean, my belief is that Tammy would have died if we had been in, if we had been at home when this had happened because no one donates here. So we have doctors and nurses that can do a transplant here, but my belief is . . . I can't tell you for sure this would have happened, but my belief is she would have died if we had been here.

It's funny, when I came back, talking to a few people, how many people that we knew that actually were, had had, or were waiting for liver transplants. Not even just an organ transplant in general, but liver transplants. My secretary at the time, I found out her husband was waiting for a liver transplant. One of my clients, his mother had recently passed away waiting.

So statistically, I don't know what the numbers looked like but I don't think it would have been good. They're few enough and far between, and particularly with a liver. I mean, there's so many people that need them and there's not . . . And with a liver transplant, they can do these live transplants where they sort of, apparently, as they do it . . . they do it a lot in Edmonton. They sort of, you have a matching donor and kind of take half your liver and put it in a recipient. You both spend a week or so in the hospital and you walk out the door with a fully functioning and full-sized liver. It's an amazing thing.

Now in Tammy's case, it was sort of a trauma case and you couldn't do the live transplant. So I mean, I don't have an empirical view I could tell you, but I don't have a positive feeling about how it would have turned out.

Ms. Chartier: — Well fair enough and thanks. I know you're not health care professionals and so that's maybe not a fair question, but I just wanted your perspective. So thank you for that.

The Chair: — Mr. Parent.

Mr. Parent: — Did we have the opt-out years ago?

Mr. Furman: — I don't think so. I'm not aware that they ever have had that. Somebody told me yesterday, though, that apparently they used to. Instead of the sticker on your health card, it used to be somehow associated with your driver's licence instead of your health card. So maybe there's a little change there. I don't remember when that happened. Somebody mentioned . . . stand around the coffee machine at the office yesterday, somebody mentioned that. But I don't think that we've ever had it here before.

Mr. Parent: — Okay. Thank you.

The Chair: — Are there any other questions? No. Okay, well, before we quit I want to table HUS 13-28, Cory J. Furman: Submission regarding organ donation inquiry, dated September 6th, 2016. And I want to thank you, Mr. Furman.

And seeing that there are no further questions, that concludes our committee meeting for today. We will resume our public hearings in Saskatoon on September 12th at 9:45 a.m. I would now ask for a motion to adjourn.

Ms. Carr moves this committee stands adjourned until Monday, September 12th, 2016 at 9:45 a.m.

[The committee adjourned at 09:55.]