STANDING COMMITTEE ON HUMAN SERVICES

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STANDING COMMITTEE ON HUMAN SERVICES

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Public Hearings: Improving Organ and Tissue Donation Rates in Saskatchewan

[The committee met at 09:44.]

The Chair: — Well good morning, everyone. Welcome again 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 that are here today. We have Mr. Buckingham, Mr. Docherty, Ms. Chartier, Mr. Fiaz. We have, substituting for Ms. Wilson, Ms. Carr. We have Mr. Olauson substituting for Mr. Parent, and we're going to have Mr. Forbes substituting for Ms. Rancourt.

Today we're continuing our public hearings on how the Government of Saskatchewan can increase the rate of organ donations and improve the effectiveness of the organ and tissue donation program in Saskatchewan. And right now the committee proceedings will be live-streamed on the Legislative Assembly of the Saskatchewan website and archived video proceedings will be available. The committee's website can be accessed by going to the Legislative Assembly of Saskatchewan website at www.legassembly.sk.ca. Public documents and other information pertaining to the hearings are also posted to the committee's web page.

Our first presenter this morning is Mr. James Richardson. I'd like to welcome you, sir, to the committee today. Before you give your presentation, please introduce yourself, and if you are speaking on behalf of an organization, please state your position within the organization represented. And I see 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 the tabled submission will be available on the committee's website.

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

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

Presenter: James Richardson

Mr. Richardson: — Thank you very much. It's a pleasure to be here. As the Chair mentioned, my name is James Richardson. I'm a senior manager with Deloitte in our public sector transformation consulting practice.

So the beauty of being here today is that we get to share a lot of what we've learned along the way from working in this field across the country and in different parts of the world as well. So when we saw that the Government of Saskatchewan was looking at this stage with this committee — what are some of the options; what are some of the possibilities? — we got quite excited. So I'll push up my glasses and say, oh yay. We can tell you some of what we've learned, some of what to pay attention. And we're talking a little bit more around how to think about it, how to consider what some of the options are before you, and to frame the thinking with everything else that you're receiving from these public hearings and individual submissions.

I may not be telling you anything you don't already know. So maybe just permit me to be excited about having a chance to share. So I'll just get started. When we looked at what has the committee already seen, what have they seen from administration, on June 2nd from the administration you had a number of different options that were put forward, different tactics that could be considered. And quite frankly, we don't disagree with anything that's on that list. What we want to reinforce is that the best way to increase and maximize donor potential is the systemic approach, not an individual. There's no magic bullet. There's no silver bullet that can just do one thing or one or two things and get there.

So what we have next here is we've put the 17 core functions of a highly effective organ and tissue donation system. So we've mapped them out, and there's a method to the madness, if you will.

So the top line, what you'll see there underneath the donor and donor family, because everything is centred around that, the top line is front-line service delivery. So when a donation opportunity arises, this is the value stream or the straight line of functions that must be performed to ultimately get to transplant. So from identification/referral, you know an opportunity has been identified. It's referred to the team or the organ procurement organization that's going to take a lead with the donor coordinators, then through approach of the family and then obtaining consent ultimately. And then after that it moves through the process of screening and matching, organ recovery, storage and distribution.

This is a bit of an anomaly sitting there because it applies much more to tissue donation than it does to organ donation. So an organ, once it's been recovered, it's between 24 and 48 hours from recovery to transplant. Tissue donation has the ability to store and there's, you know, a bit of storage logistics and distribution that can happen there, some tissues up to five years. So there's diverging paths but ultimately the same end result to a transplant. Then organ and tissue utilization would be kind of the end of the donation process and the very beginning of transplant.

The second line, here where we have five functions there, is the enabling supports. So these supports, what we've termed here is this is what needs to happen in behind, directly in behind those front-line service delivery. So public awareness, obviously that would have an impact when you're going for approaching consent. Is the family aware? Do they believe in it? How is that going to affect consent?

Hospital engagement. Hospital engagement is about engaging the executive, the administration, clinicians — that's physicians and nurses — making sure they're aware of what it is, why we do it, how is it important, and who is involved.

Provider education, similarly in there as well. So it's being very deliberate about getting to those people that will be involved in that process to help them understand policies, procedures, you know, who the stakeholders are. So that’s policies and procedures, pretty self-evident.

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

The bottom line is the system supports, so systemic supports. And you’ll note that’s where the registry is sitting. The registry is not sitting in the middle line. The registry, we haven’t seen in all of our cross-jurisdictional research, in talking to different organizations, it doesn’t have a direct causal effect. So in other words, the number of people registered does not mean you get a higher level of donation. You can have a million people registered, but it doesn’t necessarily mean you’re going to move the needle on donation. Not to say that the registry is not important; it is a very important tool for public awareness, public engagement. It’s something tangible that you or I can do once we have learned something about it and then the importance of donation. And it is, you know, a good metric to measure how aware and how engaged is the public.

Performance management, quality assurance. Quality assurance is what needs to be measured and why. Performance management is the actual tasks, metrics, and processes of measuring.

Research. So that’s partnering with other organizations, post-secondary, again in the research into the system, making sure that it has an impact on continuous improvement.

IM/IT [information management/information technology]. Fairly self-evident, but the organizations and jurisdictions that have a robust IM/IT system that helps support the process, that top-line piece — as well as capturing the data, looking at the performance metrics, understanding how is that quality assurance happening — can move the yardstick and get some of those improvements on the continuous improvement and once you’re into that point.

Then lastly, probably of greatest import to this committee, legislation and provincial policy. So strong legislation is, you know, that keystone for the governance that sets it up to be successful in the way that you want to have that working in your jurisdiction.

So that’s a quick overview of the 17 functions. I’ll come back to it in a moment.

So here we have, you know, this is one of these charts that we just love. Yes, we look at it and we put a whole bunch of things into one place. And what this is, this is a view of a number of different jurisdictions that we actively engaged in and talked to them about, how do you operate? What are the impacts that you have, and what’s working really well to have a good donors per million, the donation rate in your jurisdiction?

So there’s, you know, a good number of Canadian content. Not all of them are top performers, but many of them are. And then we looked at a couple in the US [United States]: LifeCenter Northwest, which is over in the Seattle area, and then Philadelphia as well. Spain, you know, I’ve seen in many of the literature that you guys have been looking at already. Spain is a top performer as far as donors per million. They may count it slightly differently than we do in Canada and North America, but regardless they are held up consistently, and through our research as well, as one of the leading jurisdictions around organ and tissue donation. Then UK [United Kingdom] and Australia.

What the big take-away from this table is most jurisdictions that have a great result and are performing really well on tissue and organ donation have some degree of stand-alone organization. And stand-alone organization, there’s a couple of instances there where you have the ball that’s only half full. And that’s somewhere like a hybrid between, you know, government and fully independent. The ones that are completely filled in, those are independent organizations. So it could be a Crown corp. It could be a stand-alone organization, and different ways of doing that.

But also you’ll see very consistently, everyone has donor coordination, a donor coordinator. Typically that would be a registered nurse in part of an organization inside the individual hospitals. They’re the ones that are highly trained and know what the process is, how to do that approach and consent and how to move it through the process.

Clinical leadership is also important. And that’s typically a physician, a physician charged with leading the operations and making sure that things are happening and happening well at the hospital level.

So if we come back to the 17 functions, what we have found is there are a few high leverage points when you’re in the situation where you’re saying, we’re not happy with the rate of donation in our jurisdiction. Where should we start? Where should we start and put a lot of emphasis on our efforts while also looking at the rest of the system? But where do you want to put more resources? So we’ve circled here, on the top line, identification referral, approach and consent. That’s because if you don’t do those well, you don’t have much left that’s moving through the rest of the processes. So you know, options like mandatory referral can be helpful, but someone still has to make sure it’s been identified for it to be referred to the process and to the system.

Approach and consent. What we have found when we looked across jurisdictions and engaged with a bunch of different programs, how you do that approach and then obtain that consent really, really matters because now you’re looking for a conversion rate.

You can go and talk to a family and there’s, to put it bluntly, a big difference between, so can we take his organs versus making sure they understand what is this all about: what are the potential, how did Joe or Mary think about organ, tissue donation, were they interested in a legacy of really transforming up to seven or eight lives through organ donation and many, many more through tissue donation? So there are leading practices on how that’s done, what some of that script looks like, who should engage, and how you should engage those families. That makes a big, big difference, converting from approach and consent and then getting increased donation. That's on the top line.

So how do you that? That's through the hospital engagement that we talked about, on an individual hospital basis, because quite frankly that's where the donation's going to happen. You need to have an eligible death, which is only 1 to 2 per cent typically of deaths that occur in province or in a hospital setting. And within that, you need to have certain conditions that are existing as well. So someone needs to be on a ventilated unit. And if they're on a ventilated unit, making sure the staff that are tending and caring for that person understands this is an opportunity. Can we identify that, refer it, and then move it through approach and consent?

Provincial coordination, like I mentioned before, that's stepping up from one individual hospital and then going macro saying, are we being consistent? Do we have consistent thinking and support for this across the province? Can we anticipate seeing similar results in similar situations?

And then along the bottom line, how do you know if you're doing well? How do you know if the provincial coordination of the education is working? That's where we, you know, circled the performance management, quality assurance, the IM/IT systems that can help keep track of that. And then, what does the legislation say?

One thing that we saw in Alberta, they enacted an amendment to their organ and tissue donation legislation. They established that there would be a stand-alone organization, so the Alberta organ and tissue donation agency. But what we found as we're working through some of the implementation is they missed a piece of giving that agency natural person powers. So without natural person powers, and a couple of lines that needed to be in that legislation, it became difficult to set them up as a separate operating organization until you amend that legislation. So we circle that because it's really important to get that right depending on the path that you want to take. So that is about, you know, mandating how it's going to be done, who's going to do it, and what powers they have to move forward.

[10:00]

All is not lost in Alberta. They still have, you know, kind of an incubated model inside of the ministry, and they have great relationships and they've done a lot of stakeholder engagement. So they can still support and coordinate the process. And it's just a question mark on how do you want to move towards, you know, full stand-alone or that hybrid model they currently have right now.

Lastly, if we look at an overview of what works and what doesn't. So now we're going to go and look at everything we've learned from looking across the globe. I mentioned: strong and enforceable legislation, standardized policies, forms, definitions. You know, what we've seen when you have a larger jurisdiction, especially with multiple health authorities or zones, you could have policies and procedures that meet their accreditation standards. There's never any doubt on that. But when you have some differentiation between one part of a province or another, then it gets a little bit more difficult on that provincial coordination piece to say, are we comparing apples to apples? You know, is one thing working better than the other? So standardization is important.

Physician engagement. So in our health systems, the physicians always have very strong leadership roles. So engaging a physician that's going to take that leadership and drive some of those processes and the process of implementation forward makes a difference, because just as much as their leadership can be positively impactful, not engaging them and not getting them on board can also have a negative consequence as far as the ability to effect real change.

Consistently, whether it's in Canada, in the US or elsewhere, engaging beyond just the physicians in hospital also matters. So the interactions with partners. That includes the hospital administration but also medical examiners. So medical examiners, why do we talk about that? That's where there's great opportunity for tissue donation, because tissue donation can actually happen up to 24 hours post-mortem, after you die, in a lot of cases.

As well as EMS, so the emergency medical services or ambulance process. It's not about chasing ambulances but it's about understanding if this is a highly traumatic incident that is, you know, likely to lead through that process. Getting that heads-up enables the donation program to start looking at, is this an opportunity or is this a time when we're going to start engaging that family early, the right way? So building that relationship, building that rapport so that if it too carries on and the care provider of that person that's been in that traumatic incident is not going to be life-saving any more, how else can that person save lives? How else can they transform lives through the process of donating their organs and/or tissues?

We always say, focus on those first steps of donation, those first steps being identification, referral, and then the approach and consent. You can do that by making sure you have well-trained staff that are going to be involved in that program and also the education that goes throughout the rest of the system as well.

Dedicated donation resources to support that hospital staff. So it's a big long way of saying the emphasis on the provincial coordination. So what we've seen in other jurisdictions is that provincial or that regional, depending on what the individual country looks at, have the ability to say okay, here's the leading practices. If you have turnover in an individual hospital or an individual location, we can make sure that they're going to be well trained and they have access to what works and what doesn't, and what we're learning.

The reason for that is when we're talking about specifically organ donation, that's a rare occurrence, so you don't have a team or a unit or a division in a hospital that sits on standby waiting for that to happen. When the opportunity arises, you pull from existing resources. And typically the programs that are high performing, they have well-trained resources that do that, and they have other jobs, you know, on the side. But they'll come in, they'll deploy . . . It's an ad hoc team, kind of kind a SWAT [special weapons and tactics] team approach: go and do it, and then disband and you go back to regular work.

So putting that in mind, those occurrences — rare, ad hoc — has to come together. Who's going to make sure, and how do you make sure that the people that will be involved in that are well trained and well prepared to do so, and to do it really well.

Not in all jurisdictions, but that last point around a single toll-free number, that's another level of triage or another approach that you can take if, especially at identification, referral, if it's been a while since you've looked at it or experienced that before. You have a resource to go to saying, is this one of those times? You know, this is what I'm seeing. This is what could be possible. Do we initiate anything or do we just leave it alone for a while? So a bit of that triage and a bit of that support.

So conversely, what doesn't work? What should you avoid? Some of the pitfalls that we've heard from other jurisdictions and other organizations. So weak or inconsistent data reporting or lack of performance indicators and targets. It gets difficult to know what things that we're doing — are they working or are they not? And it also means that it gets difficult to compare and get some of that support when you step up from a provincial basis, a regional basis and start looking national.

All of these programs already have to report, and what we've seen in many instances is some of them it's on Excel spreadsheets. It's in manually input data and information. That's not bad but it also means, think about now how much time they're spending on data input, data management, rather than health care and patient care delivery.

What we have also seen is, when you're looking at it from the sub-regions or regional health authorities or individual zones, saying well, we really like this one from the North so we're just going to apply it right across the province. You're going to have some major change management and implementation processes because saying, well hang on, how come her policy is better than my policy? And there's only a slight difference. So there's a process of actively engaging, comparing, contrasting, and saying, let's focus on what could be the best because we want to get to standardization so that we can all do better. There's a process and there's time involved in doing that. That will get you, ironically, quicker to where you want to be than just taking and imposing.

Thirdly, lacking mission and vision. A couple of conversations prior to this. There's no lack of support from the public. You see, like, 90 per cent-plus when, different times of being polled, saying they support organ and tissue donation. But we don't see that same rate in the actual donation. When you're talking to the health system itself, they're saying lookit, I agree with this but tell me what I'm rallying around. What's the mission? What's the vision? Where are we going? So that when I have to, you know, get started and get initiated in one of these opportunities, I can say yes, I'm part of this. It actually makes a big difference.

And then lastly, trying to meld the practices from existing organizations rather than building from the ground up. Again it's really about a change management process, imposing rather than bringing people along. I like to call it . . . There's three types of change. There's change that's done to us, change we do to others, or change that we do to ourselves. The third one is always the most effective. Bring people along, create the conditions where they can consider and look for the right things, get alignment against mission and vision, and you will see progress and you will see, you know, a difference being made.

So at this stage when you're receiving information from the public, persons like myself, testimony, what we really feel at Deloitte is, ask some key questions. So what kind of change are you really looking for? Are you looking for incremental change or transformational? And the reason for that question is that'll direct next choices that you make. If you're looking for incremental for any number of reasons, whether it's the degree of investment that's available or the change you're looking for, take a few tactics and, you know, look for a way to do it. If you're looking for transformational, I think you need to have much more broad considerations and deeper thought given to how you're going to proceed.

One thought that may not be totally popular — but it is drawn and there is precedent — is, should you pursue these changes alone or partner with another province and look at how could that work? So typically we don't see that in Canada because especially around, you know, health delivery being a provincial jurisdiction. But there's been great success actually and that's why we have those two pieces up from the US, so LifeCenter Northwest and also Philadelphia Gift of Life, because they actually take a regional approach. So if you look at, you know, the area they serve, it's kind of drawing a circle around a population density and a population group that crosses over . . . I think on Philadelphia, it's about five different states. But the beauty of having a stand-alone organization is they're not attached to any single one of those individual states. They're focused on supporting and coordinating donation and looking to move that needle and keep that operating really, really well for that area.

So then based on those first two choices then the next question would be, how do you want to govern? How do you want to govern these efforts? Do you want to look at it from inside the ministry? Do you want to look at it from one of the health authorities, or a consortium of health authorities, or a newly created organization? There's a few different choices available depending on what you want to do in the first two choices there as well.

I would emphasize that a stand-alone organization has proved to be the best and consistent across high-performing organ and tissue donation organizations or jurisdictions just because, especially in the Canadian context, the ability to live between policy and delivery means that you don't have necessarily the individual bias or perceived bias on either side. You're strictly focused on this piece that has to look into the system and all these different activities that happen in different places. And there's no one division; there's no one unit; there's no group that's actually going to do this. They say, we're just here to help you be exceptional and that works well.

That's the nature of my presentation at this time. I'd be more than happy to take any questions for clarification, or if I've missed something, or if you want to have other questions as well.

The Chair: — Do the committee members have any questions?

Ms. Chartier.

Ms. Chartier: — Thank you, Mr. Richardson, for your presentation. It echoes a lot of what we've heard from a variety of stakeholders. The transplant program actually just talked a lot about the need to separate transplant from donation and have stand-alone organizations. I'm wondering about your thoughts on our enabling legislation right now, *The Human Tissue Gift Act* which hasn't been proclaimed yet, but they are in the middle of developing regs. Do you have any perspective on how that fits with other legislation in other jurisdictions? What else might need . . . Are there amendments that need to happen in that piece of legislation?

Mr. Richardson: — So if you look at . . . It was strictly through the lens of provincial coordination. I didn't see anything in the current Act that talks to that point. So who is going to coordinate? What is the mandate, you know, what is the role of an organization such as that? Whether it's saying it's the ministry that does it or, you know, pick any different kind of governance possibility, I don't see anything there. So without that enabling legislation it will be difficult to move forward with that when you start engaging with the system saying, well hang on, where does it say that you should or I should or he should do this, that, or the other? It's not in the legislation.

Ms. Chartier: — Okay. Thank you. I do have other questions, but I know my colleagues do too.

The Chair: — Mr. Buckingham.

Mr. Buckingham: — Thank you for your presentation. More information to work with for all of us. So I just wanted to get your opinion on an opt-out program. We've heard a lot of information on that. I guess maybe from a position of how well it's going to work, but also maybe from a legal perspective, if you could share that. Like, you know, if there would be a challenge that you would see coming forward if we were to do something like that. Just if you wouldn't mind answering those.

Mr. Richardson: — Yes, absolutely. So the most famous opt-out jurisdiction would be Spain, and what is interesting about the Spanish experience is when they implemented that legislation, when you look back and do the reverse analysis, it was about 10 years before they had a major difference in the donors per million or the donation rate. So again it's not a causal effect between opt-out and opt-in.

And we also haven't seen, looking around the world, even with an opt-out type of legislation . . . and opt-out means that you're automatically a donor unless you've registered to not be a donor. It's typically a soft implementation. And what I mean by that is it's kind of counter to medical ethics to just automatically go in and say, this person is brain-dead, therefore let's bring in the team; let's do organ retrieval. There's still that approach and consent. You still approach the family, work through that piece when you're looking for consent from the family.

Now in opt-out or even where you have a registry, those pieces can help facilitate the conversation. Because, you know, say in Spain, you have a culture where they've decided and they've now normalized it that we are more likely to be an organ donor than not. So you can imagine what impact that has on the conversation when you're approaching and looking for consent.

Similarly for a registry, if I've registered my intent — and I have registered my intent to be an organ donor — when that piece comes up, hopefully I've also talked to my family so my family knows those wishes. But if that conversation didn't happen, the donor coordinator can check the registry and they can build that into the conversation with the family saying, did you know that James registered his intent to be an organ donor? This was important to him. Let's talk about what that looks like in moving through that process. So it can help that conversation.

But typically opt-out, when this committee is looking at it, I think we can draw lessons from the UK. The United Kingdom looked at, should we implement opt-out legislation? And they did some comprehensive research including looking at Spain, including looking at other jurisdictions, and ultimately decided not to because of, to your point, sir, what you were talking around. What could be some of the consequences? What could be some of the public perception? What could be some of the public feedback on that? Decided it's not worth it; we don't see the causal effect that it's worth pursuing that, implementing and standing by it, to get the result that we're looking for.

So ultimately they decided to leave it as opt-in and then invest it further on public awareness, so helping the public understand what is the true benefit, what can be great about doing this, how do we transform those lives afterwards by increasing donation to ultimately increase transplantation. Does that answer your question?

[10:15]

Mr. Buckingham: — Yes, thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you. I think one of the things that has come out as a theme, I appreciate your comments about no silver bullets. You give us the cross-jurisdictional snapshot and there are many pieces to a high-functioning organ donation system: donor physicians, the mandatory referrals. The opt-out piece is interesting for sure.

I know as a committee member, the challenge has been put to us by many people, usually those whose lives have been saved. We've had many people who have lived experiences who have said, well if it was your son or daughter, wouldn't you want opt-out? But my perspective is I want the system that ensures that there's enough donors, and I don't care if it's opt-out or whatever it is, those pieces.

But I'm wondering about where donor physicians fit in your . . . You talked about clinical lead and the donor coordinator. I'm just curious if the donor physician . . . You said the donor coordinator is usually a nurse. And then would the clinical lead be those donor physicians?

Mr. Richardson: — Typically yes. And what we've seen is often that leading physician . . . a better idea not to be a transplant surgeon because it gets to be perceived as a bit of a conflict of interest because donation is the supply for transplant.

But a clinical lead, so a physician for the donor program, typically you'd see in acute or intensive care because they already live in some of that reality and they can understand some of the instances. They have some of that family interaction leading back into those first two pieces — identification, referral, approach, and consent — and then also have that interaction to see it all the way through and to be able to understand the impact it has once it moves all the way to transplant, and then the lives that are transformed.

People that were in hospital, sitting in a bed waiting for a transplantation, obviously it costs in the health care system on a daily basis on the financial side, but also they have a life-cost side where they cannot live the life they're looking for. You get that transplant, that's a transformed life for that person and their families, and it's also a cost deferral for the health system as well. Now you have a much lower cost for making sure that they have their health and wellness to move forward.

Ms. Chartier: — Okay. Just one last question from me — sorry, thank you — around registries then. So I'm hearing that those are good communication tools or public awareness tools to start the dialogue with families even, but again no silver bullet.

I'm wondering, so BC [British Columbia] on your cross-jurisdictional list has a registry. How does that tie in, sort of into a regional approach or the CBS national registry?

Mr. Richardson: — So I think the CBS national registry is more of a transplant registry. These regional ones are donation registries. So BC has one. Alberta also has one. Alberta is also working with NWT [Northwest Territories] to have, you know, their system being the back end for what NWT has, public facing. Two things occur. So when that's a starting point, it can be a rallying cry for the system saying, okay we've done this. Look at the number of people. So it's, you know, empirical data that says more and more people support this. And you can watch those numbers grow.

And then also when you're doing public awareness activities, wherever that's done from, that's a key part. So when I find out, oh that's what organ and tissue donation is like, and I understand what the process is and the impact and what a wonderful and noble cause that can be, now I have something to do. So me, as James in the public that's just been made aware, I have something to do. I can go and register my intent. But that intent again does not translate to an automatic donation if the eligible death occurs, but it does support that approach at consent conversation.

Ms. Chartier: — Are they stand-alone registries or tied into eHealth? So how do BC and Alberta . . .

Mr. Richardson: — BC, I think they're both . . . They're stand-alone registries. So in Alberta it's a stand-alone registry and it's managed by the ministry. Because what we've seen as well is if you have a stand-alone organ and tissue donation organization, they don't need to manage the registry.

Ms. Chartier: — Yes.

Mr. Richardson: — And in fact it's probably better if they don't. What they do is they set up the report, making sure they have access and that, more importantly, at the front lines a donor coordinator can access, through privacy protection and everything else, but access that registry to find out how that's going to work through their process.

Ms. Chartier: — Okay. So one last question on the registry piece then. So hypothetically let's say I'm on that registry and I'm in the hospital and death is imminent. Does the transplant . . . Who accesses that or who knows that Danielle Chartier is on that registry?

Mr. Richardson: — Typically what we've seen is access is only given to the donor coordinators, potentially the physician lead as well, but they're not usually the one accessing it. So it's just the donor coordinators that would go in, access that, and see if you've registered your intent or not.

Ms. Chartier: — Okay. Thank you very much.

The Chair: — Mr. Docherty.

Mr. Docherty: — Thank you, Mr. Chair. Mr. Richardson, thanks for the presentation. You talked about a team, a group of professionals that would be part of this group. You called it ad hoc, potentially, like a lot of times they might be ad hoc. And I'm wondering how we balance that in terms of the economy of scale because you've got a number of professional medical personnel that might have other jobs, as opposed to dedicated just for transplant and tissue, and knowing full well that, how often in the course of a day is it going to come up?

Mr. Richardson: — Yes.

Mr. Docherty: — So how do we balance that, knowing full well that we've got people that we want to be fully engaged in their practice, and at the same time wearing another hat ultimately, but knowing full well that the model we want is a dedicated team?

Mr. Richardson: — Yes.

Mr. Docherty: — So how do we as a system, as government, balance all of that? What are your thoughts?

Mr. Richardson: — So my thoughts on that and from what we've seen both through, you know, working with organizations through their implementation, looking at how they work with into the health system, is you need to separate the governance and the operations. And even there is a bit of a blurry line as well. So what I mean by that is a stand-alone organization, you can define what's in and what's out of that. So are they going to just support and coordinate and help individual programs at a hospital level to manage their work, or do you take some of that on and keep that into one organization looking at the whole region, in this case all of Saskatchewan, and say what we need from you is just when it's time for a donation that you have a donor coordinator? And that donor coordinator is well trained, understands what the process is, and can follow those . . . [inaudible] . . . practice to go and do it. But you take the administration up to the stand-alone organization.

What we've seen in Alberta is they have a bit more of a hybrid model. So you'd have a small core of people, some in the North, some in the South. So there's two or three people that are running the program looking at some of those mid-line pieces — so the hospital engagement, also the bottom line of performance management, quality assurance, standardization of policy, all that stuff. But you have a core team of maybe two or three at a hospital level, and also inside of that would be the donor coordinators as well. So they may be part time in this hospital level organization and the rest of their time is fulfilling typical care needs at whatever division of the hospital they're working in.

So it's a great question and it kind of depends on how you want to do this and where you want to go and you have to really consider that. What are we working with? Who's available? What's already happening, and then what makes the most sense?

Mr. Docherty: — Yes, it's vital. I mean this coordinator position is absolutely vital. That particular person and the skill set that they bring to the job is vital because they're basically the hub in terms of a number of pieces. To get that type of person and to keep them, I mean it's . . . If you find the right person . . . This is all relationship-based, and I consider that approach is absolutely vital.

So you know, you've helped. I was having a difficult time trying to envision what this might look like in Saskatchewan, but I thank you for that because it's cleared up some things for me, so thank you.

Mr. Richardson: — Great.

The Chair: — Mr. Buckingham.

Mr. Buckingham: — Thank you, Mr. Chair. Just wondered with respect to your cross-jurisdictional snapshot, under donation committee, what does that look like in other provinces, other countries? Can you speak to that a little bit?

Mr. Richardson: — Yes. So the donation committee is typically at a hospital level, and depending on the government's framework, you might have a rep from an individual hospital level that comes up to the provincial level as well. And that donation committee would typically have representation from transplant, but the majority from the donation process. And that would include both hospital administration, so those not involved in direct care delivery. But you need that leadership support to make sure the program is well supported and it, you know, permeates through the system, but also donor coordination, the organ procurement organization. I'm using that very generic term because it depends on where it is: could be at a hospital, could be a provincial basis.

But also it extends into the clinical leads, so at the physician level and also some of the secondary health care as well. At the social worker level as well, because sometimes an RSW [registered social worker] makes a very great person to do the approach and consent or being involved in that team that looks at doing that.

There are specific tasks that start occurring once you get into after a consent. And you have to do the screening and matching and following the accredited standardized policies and procedures, that now you do need an RN [registered nurse] because you're dealing with a lot of labs and different medical pieces.

But assembling that committee, getting representation from the whole system that has to be engaged to make sure this does really well, that's your opportunity to saying, how's it working? Where do we see some roadblocks? Who's the best place to do that? You have a clinical lead at the hospital level and then you have an organ procurement organization that's looking at, okay, well we saw hospital X and we're talking to hospital Y; we can bring some of the leading practices in. Does that answer your question?

Mr. Buckingham: — Yes, it does. Thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you. You posed the question to us as a committee and as government in general, do you want incremental change or transformational change? And obviously we're at the bottom of the pack here and have much room for improvement. I'm wondering what, in looking at your cross-jurisdictional snapshot and thinking about transformational change, what do you see us needing to do?

Mr. Richardson: — So I would come back to the emphasis on, determine what stand-alone organization makes the most sense.

There's a couple places that you can situate that. There's different ways you can govern that. You do want to consider what is the level of investment compared to the return that you're looking for because, let's face it, it does come down to what budget is available to support such initiatives. But the investment is not just around seeing the numbers of donation go up. That's something that's, you know, front and centre, and I think a good public-facing metric.

But what actually happens when you increase donation? First of all, it allows you to play more thoroughly on the national stage because when a donation actually occurs, it moves up to the national level for allocation as to where is the highest need, and there's algorithms that are managed by CBS on that. Sometimes it will come back locally; other times it may go elsewhere.

But the ability to do that well, the ability to increase the number of donations means that you can play better at the national level and bring more of the organs to be allocated back into Saskatchewan. And when that occurs, when someone gets a transplant, someone who's been sitting and waiting for a while, you are going to start removing some of those costs from that patient in the health system.

Now, we are careful with the language because there's . . . it's cost deferral. Because, let's face it, an empty bed doesn't stay empty for long. But it's moving people through; it's that throughput and taking people back to having the choice on how they want to live their life, getting out of the hospital bed and back to contributing members of society, and some of those other offshoots that happen there as well.

So how do you do that? A number of different ways. You can look at, you know, can you get champions at each of the individual hospital levels where that donation's going to occur? How do you herd those cats on a consistent, deliberate, move-forward approach? What we've seen is to having some degree of stand-alone organization that has mandated and has the appropriate enabling legislation to back them up, is what can act to move that forward.

Ms. Chartier: — Thank you.

The Chair: — Seeing no other questions, I want to table HUS 27-28, the Deloitte submission regarding organ donation inquiry. Thank you very much for your presentation, sir.

We'll take a very short break while we get ready for our next presentation.

[10:30]

[The committee recessed for a period of time.]

The Chair: — Our next presentation this morning is by the Kidney Foundation of Canada, Saskatchewan Branch. I'd like to welcome you to our committee today. Before you begin your presentation, please introduce yourself and your position within the organization. And 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 to the committee's website.

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

Our agenda allows for a 30-minute presentation, followed by a 15-minute question-and-answer period. Before we get started, I want to table HUS 28-28, Corrine Pankewich: Submission regarding organ donation inquiry, dated September 13th, 2016. So ma'am, if you'd please proceed with your presentation.

Presenter: The Kidney Foundation of Canada, Saskatchewan Branch

Ms. VanDeurzen: — My name is Joyce VanDeurzen, and I'm the executive director of the Saskatchewan branch of the Kidney Foundation of Canada. And I'm also the executive director of the southern Alberta branch of the Kidney Foundation of Canada. So that may come in handy with some of your questions.

First I want to start by thanking you for the opportunity to share some of our thoughts and knowledge and recommendations on improving transplant rates in Saskatchewan. On December 11th, 1963, Canada's second kidney transplant was performed at St. Paul's Hospital in Saskatoon. The same year the first hemodialysis treatments began in the province, also at St. Paul's Hospital.

In 1989 the Kidney Foundation of Canada provided the seed funding to hire the first organ and tissue donation and transplant coordinator for Saskatchewan based in Saskatoon. We're very proud of the role that the Saskatchewan branch and the Kidney Foundation of Canada has played in promoting and moving forward organ donation and transplantation.

Organ donation is a cornerstone of our mission. It's not something we think about once in a while. It's one of the pillars of the mission of The Kidney Foundation of Canada. That's because 75 to 80 per cent of the people on the waiting list for an organ transplant in Canada are waiting for a kidney. We're proud of Premier Wall and the government and elected representatives for their determination to make real change and their commitment to increasing the number of transplants in this province.

As you know, a kidney transplant is the best therapy. It's the optimal health outcome for patients with kidney failure. Compared to dialysis, a kidney transplant can more than double a patient's life expectancy. It is also the most cost-effective method of treatment for patients with end-stage kidney disease. Starting in the second year of transplant, the health care system avoids between 33,000 to $84,000 per transplant patient per year of dialysis, while at the same time providing much better health outcomes for patients.

A study conducted by the Kidney Foundation showed that of 1,000 patients who were unable to work because of kidney failure, if they were to receive kidney transplants and return to work full time, their combined annual contribution to Canada's gross domestic product would be $50 million. The study also estimated that the Government of Canada would collect about $8 million in additional tax revenue per year from that employment which is obviously a tax benefit at the provincial level as well.

Improvements in the number of kidney transplants has tremendous benefits in health care savings as well as the economic benefit of potential tax revenue due to the restored health of kidney patients. Improvements to the organ donation systems in the province should be of the highest priority and could be largely self-funded through these savings and tax revenues.

I'm speaking on behalf of kidney patients and their families today. Improving transplant rates is critical. Incremental improvements are not good enough. We have known for years what needs to be done, but the will to get it done and the resources to get it done have simply not been applied. And that's not unique to Saskatchewan. I can think of no other area of medicine where evidence-based best practices in medical care and accountability for results could be disregarded such as it is when it comes to organ donation.

Organ donation is a health care crisis in Canada. People are needlessly dying. The numbers of people on the waiting list for a transplant do not truly describe the extent of the crisis. Many people languish so long on waiting lists, waiting for a transplant that never comes, with their health continuously declining so that they reach the point where their health has declined to the point where they are no longer eligible for a transplant. They are taken off the list. Again, people are needlessly dying. We can and must do better. Incremental change is not good enough. We need to transform the systems required.

This has been successfully accomplished in other countries. The evidence, the best practices, the road map to optimizing donation is there. It exists. It's not like we need to conduct an experiment to figure out what works. What works has been proven elsewhere. It now needs to be implemented here.

The systems of those countries with the highest deceased donation rates share similar features, and I see you've already heard about some of those. Most importantly, I'll list a few of them off. Mandatory referral. Also the presence of in-hospital donation specialist teams who are accountable for performance and quality. Accountability is key.

Optimized programs for both types of donation, donation after cardiocirculatory death and donation after neurological determination of death. It has been estimated that implementing donation after cardiocirculatory death, also known as DCD, could increase the numbers of organs available for transplant by 20 to 40 per cent. That alone would have that impact.

We also need highly developed and consistently implemented leading practices, practices proven to work, practices that have been proven over time that are well known. We don't really need to conduct an experiment in Saskatchewan. This has been proven elsewhere — in some cases, such as Spain, more than 20 years ago.

And also of course we need public and professional awareness and education. We are not championing or recommending the establishment of a consent-to-donate registry for the province, and I'll tell you why. You might be surprised to hear that.

[10:45]

There's very little evidence to suggest that these registries produce any increase in organ donation rates. The resources required to develop and maintain such a registry can be much more effectively applied toward resourcing the hospital systems that I have mentioned.

I told you I'm also the executive director of the southern Alberta branch. We have recently implemented a registry system in Alberta because the public does clamour for it. The public also clamours for presumed consent. Both of these strategies, these tactics, are based on the premise that consent is the reason why we don't have enough organs to transplant. And that is simply not the case.

A number of years ago in the '90s we did a . . . the Kidney Foundation funded a medical records review for all the critical-care hospitals in southern Alberta from Red Deer south, and we worked with the hospitals to implement a process used in Spain and in other areas for monitoring. We funded it. We brought in professionals — that's what the funding was for — from Boston, associated with Harvard, to do this type of review to really understand what was the potential for organ donation because we're always assuming there's more, more, more.

Is it unlimited? What is it? What was the potential and then where were the barriers? Where were we failing? Because the only good reason for not securing an organ for transplant is when consent is refused. That's the right of every family to refuse consent, and we found, and it's been found — this number is fairly consistent — that 10 to 20 per cent of organs are not secured for transplantation due to refusal of consent. The others are lost through failures in our system. Those we can fix. Those we must fix. It's our duty to fix those.

And that was consistent in the US and all of these medical records reviews, death records that were reviewed. It was consistent in southern Alberta. It's been done in several provinces in Canada and the information is fairly consistent, and at that time we were retrieving about 44 per cent of the available organs for transplant. So a lot of organs lost due to failures in our systems and our practices.

We are also not championing presumed consent at this time. Evidence suggesting its effectiveness is very limited. Further study is needed before we invest the resources and take the risk of potentially turning off a public that is actually very supportive of organ donation. Study after study that's been done — we've done them; many other groups have done them — show that about 90 per cent of the population is willing to consider organ donation. Willingness is there. It's moving people from positive intent to action that's important.

And the action that's needed is not spending millions of dollars on a registry. It's encouraging people to take the next step — tell their family, I want to be an organ donor. The system you have in Saskatchewan, with stickers on the back of the health care cards, is effective. That's an indicator of willingness to donate and encouraging people to talk to their families. Those are adequate for that piece of the puzzle, we think.

We need to resource . . . We need to get busy implementing the proven systems that have been shown to work in other countries and in other provinces. We need to resource these systems adequately and we need to measure results and create accountability. What gets measured gets done. What gets reviewed, people start feeling accountable for. It's very important.

I'd like to say a few words about living donation. Receiving a kidney from a living donor is also tremendously important in improving organ donation rates. Outcomes for recipients and donors in Canada are among the best in the world. But living donation performance among provinces varies significantly.

The number of living kidney, liver, and lung donations increased steadily in Saskatchewan in 2012, again in 2013, again in 2014, and then declined to almost 2011 levels in 2015. Why? We can and must do better on this as well. What are the barriers to living donation and how can we remove those?

In 2011 the Saskatchewan government made a bold move to help remove some of the barriers to living donation by creating and funding the living organ donor expense reimbursement program for the province. All medical expenses for organ donation of course are funded through the health care system, but there are many additional costs known to be borne by living donors that needed to be addressed, and that was the point of the living organ donor expense reimbursement program.

The purpose of the program is to reduce the financial disincentives or lessen the financial burden for living organ donors. That's kidney, liver, and lung — those all can be donated by a living donor. The program is funded by the government and administered by the Kidney Foundation's Saskatchewan branch and we do not charge any administration fees for administering this program at all. That is our contribution to helping make sure that that program works effectively and is administered effectively for all living donors in the province. I think it has had a good impact. We table annual reports on that and those are available to you.

Improved public awareness and professional education and peer support for living donors and potential donors could be quite beneficial to increasing the number of living donors. I think we've missed the boat a little bit on public education. We always focus on organ donation is good, consent to be an organ donor, those sorts of things, when we know actually the public sentiment is kind of already there with that.

Again we've done study after study capturing public willingness and sentiment. Now we need to start talking about public education tailored to potential living organ donors because many people don't consider they could be a living organ donor but would if that possibility was put forward to them. We get calls in our office regularly about people inquiring about how do I become a living donor. Public education tailored to the specific needs of various cultural groups would also be most important. There's different needs for different groups.

Speaking about living donation, we also need to reduce the amount of time it takes for a potential living donor to be screened and tested as a match. The more barriers that exist for a potential donor — such as the length of time between their expression of interest and the beginning of the matching process, the number of medical appointments required prior to donation — the more inconvenient and burdensome it becomes for potential donors, especially if they're having to travel around the province since that testing can be done in Regina or Saskatchewan. Also the best and highest standards and protocols for customer service need to be applied to the living donor and the donation process. This is a tremendous, generous gift and these people should be treated accordingly through the system.

The Kidney Foundation of Canada also has a very highly developed and well-regarded peer support program. This is also an important support for potential living donors. When they are considering becoming a living donor, there is nothing more powerful than speaking to someone who has already done it. That's the person that can best answer some of their questions about what the process was like for them and their recovery. Of course they are very well supported medically with the medical systems that are in place and all of the resources that do exist already in Saskatchewan. But there's nothing quite like speaking to someone who's already been through it.

The optimal kidney transplant is a pre-emptive transplant where the person receives a transplant just prior to needing to begin dialysis treatments. Living donation makes this a true possibility. That's the optimal health outcome, and of course the optimal economic situation as well, in terms of health care costs.

We need to truly create a culture of organ and tissue donation in this province. Every single family should be given the opportunity to consider organ and tissue donation upon death. This must become an essential end-of-life care practice in this province. It must be adequately resourced and the accountability for outcomes must be applied.

Living donation must be promoted, complemented by excellent education which is culturally appropriate, and supported by an effective peer support program. Living donors must have quick and easy access to the supports they need, reducing the barriers to living donation.

I will say that I've been working with the Kidney Foundation for the past 29 years. I've served on our national task forces around organ donation for all of that time, and I'm very familiar with the models that have been highly effective in Spain for more than 20 years. In the last number of years, Croatia has had a tremendous change to their outcomes and to the number of organs available for transplantation. Australia, the UK . . . we should be leading the way on this ourselves.

The Kidney Foundation has a very bold goal: to increase the number of transplants by 50 per cent by 2020. That is absolutely achievable. That was done in Australia. It was done in the UK. And it's really based on the model from Spain, where all the success is based on the elements of that model and tweaked and perfected for the local country or jurisdiction. So that's what we need to be looking at. That's what we need to be doing.

In conclusion, I call upon the government to be bold and courageous — implement these proven best practices, measure outcomes, insist on accountability, truly make increasing the number of transplants and increasing organ donation rates from both deceased and living donors a true priority. The funds invested in this transformation will be more than recouped in health care cost savings and through increased tax revenues generated by transplant recipients who can return to work once their health has been restored. The benefit of positive health outcomes and lives saved through organ transplants is priceless.

Those were some of the thoughts that I wanted to share with you today on behalf of kidney patients and their families in Saskatchewan.

The Chair: — Well thank you for your presentation. Ms. Carr has a question or questions.

Ms. Carr: — Great. Thank you very much for your presentation. So most of the conversations we've been having have been about donation from people that have passed on, so I'm really glad that you brought to the forefront the living donation and the fact that 75 per cent of the people on the list are actually waiting for kidneys. So that highlights it a little bit more.

You listed off a number of things that Saskatchewan has that probably we're doing well, but it doesn't sound like we really have a well-coordinated effort to make it flow more, I guess, better. You talked about Spain and different countries that are doing it very well, and I hadn't heard about this part of it in any other presentation yet. So are there resources or things that we can get from them to show how we can coordinate our system better without, like you say, reinventing the wheel when it's working somewhere else?

Ms. VanDeurzen: — Exactly. All of these countries have been very generous in sharing the systems that they implemented, the things that really made a difference for them. And Spain has been the most generous of all because they've been sharing this for more than 20 years. And that information is readily available, and really the gist of it consists of those things that I listed off that need to be implemented in the systems. And then there's the nitty-gritty detail in each of those points as well that is readily available.

I believe in Saskatchewan the system needs to be a provincial system, province based. It has enough critical mass that way. It can't be implemented health region by health region. It really does need to be a province-wide program run in a highly coordinated way, but it needs to be implemented on the ground in key hospitals.

Ms. Carr: — Thank you.

The Chair: — Mr. Docherty.

[11:00]

Mr. Docherty: — Thank you. Thanks for the presentation. I was going to dovetail on my colleague's comments in relation to your comment in regards to best practice and evidence-based research. And you prefaced some consideration in terms of studies, and I'm wondering if you could provide links and/or resources in relation to the studies that you've referenced for the committee's perusal.

Ms. VanDeurzen: — I would love to do that. I'd be happy to do it.

Mr. Docherty: — So yes, we can figure out how that would . . .

Ms. VanDeurzen: — We'll coordinate that.

Mr. Docherty: — Work in terms of studies. But yes, you've already done the lion's share of the work. So we would appreciate the opportunity to again learn from what you've learned and what other jurisdictions have brought forward. You've referenced a number of — excluding Spain, obviously — but you've referenced a number of Commonwealth countries and there would be some synergies. Not perfect, I mean all jurisdictions aren't perfect evidence-based comparators, but there are some lessons to be learned. And I think that's great opportunities for us as a province and as a country to learn from others. So if you could help with fine tuning . . .

Ms. VanDeurzen: — I'd be happy to.

Mr. Docherty: — Some of those studies for us, we'd be very appreciative. So thank you for that.

Ms. VanDeurzen: — I will do that.

The Chair: — Ms. Chartier.

Ms. Chartier: — First of all, thank you very much for your presentation. Having worked in the field for so long, much of what you've said has sort of tied together what we've heard in a few other presentations as well. Very appreciated, all your comments.

I'm interested, like Ms. Carr, in the living donor piece. We had a witness yesterday actually. So the living donor expense donation program that was implemented in 2011, when we weren't doing kidney transplants here for that little bit of time, I'm assuming that that's why that was first implemented because people had to travel.

But we had a witness yesterday who said her family had experienced much loss and tragedy around pulmonary fibrosis actually. But she was looking at becoming a living donor and said it was very difficult to find information. She talked to her insurance company and realized . . . She was trying to figure out how she could do this without a huge financial barrier. So obviously she hasn't heard about this program, or she heard about it and it wasn't quite sufficient. Is there a cap with respect to the living donor expense program?

Ms. VanDeurzen: — Yes. The living organ donor expense program, Saskatchewan was one of the later provinces to come on board with it in 2011. It had been developed and piloted in BC and rolled out in many other provinces, Alberta and then Saskatchewan coming on board a little later.

The good news about that is we were able to learn from the experience of others, and I think the living organ donor expense reimbursement program — we call it LODERP for short — here is quite good as a result of that. It helps to reimburse living donors for things such as travel expenses. So for example — and this is all to benefit potential recipients in Saskatchewan — so if a resident of Saskatchewan had a potential donor that was from another country, from another part of this country, or anywhere of a great distance, this is a big thing where this program can help provide, cover those travel costs to get that donation done. It also helps with income replacement when many people work without health care benefits or income support, those sorts of things.

This will cover . . . again, the details of the program are available. I can certainly send them to all of you. And they're consistently applied. There is a maximum amount that can be awarded: travel costs; things such as parking, parking can get expensive when you come to the hospital many times for many trips; those sorts of things involved in travel, those types of expenses; an income replacement.

So we can send you the details of what is covered by those programs. And certainly there is an annual report done on those programs: how many people have been accessing. There's no, by the way, there's no income testing. Everyone who's a living organ donor is eligible for these expense reimbursements, and the details of those are all available in the content of the program. So I'd be happy to share those with you.

And that was really an important support to the paired exchange program. I'm sure by now you've heard a bit about that. I think that's one of the most transformational things that has happened in Canada in organ donation, because before we were just losing people that would come forward as a potential living donor, be tested, they wouldn't match with the person they were willing to donate to, and now the person can't get a transplant. That person's not a match.

And instead, that person who's willing to be a donor is put into a pool, matched with someone they do match with. The recipient they were trying to help is matched with someone else, and it creates a bit of a chain of donations. And I think the biggest one in Canada to date has been 19; I could be wrong on that. But it has really helped with living donation quite a lot, in taking the positive intention that these living donors that come forward, taking that positive intention and still turning it into the outcome that they wanted, which was a transplant for someone that they cared about. So, very important, and the LODERP program has been quite important in funding that because donors will travel to other jurisdictions to make the donation to where the person they are matched with lives, if that makes sense.

Ms. Chartier: — For sure. And I think that this was the concern of this young woman who'd wanted to donate and saw a big financial burden. She'd crunched the numbers and actually said off the record, out of earshot, that she thought it would have cost her about $50,000 in terms of income replacement and everything that was involved.

Ms. VanDeurzen: — Yes.

Ms. Chartier: — But I think that that's one of the things we've heard from people who've experienced transplants, not on the living donor side, and incentivizing or making it easier for that. But the barriers — I know you work in the world of kidneys — around lung transplants, the six-week stint that people have to spend in Edmonton pre-operatively and then obviously the time afterward, thinking about ways that we could better support . . . either do some of that work here — I don't know if that's even in the realm of possibilities — or better support people in that part of their journey.

Ms. VanDeurzen: — That's right, and part of the LODERP reimbursement is for things like accommodations, for exactly those types of things. And I should mention the LODERP program is not just for living kidney donors. It's for lung and liver donors as well, and we administer it province wide for all of those donors.

Ms. Chartier: — Okay. Thank you very much.

The Chair: — Mr. Fiaz.

Mr. Fiaz: — Thanks. I have a question about, you mentioned that we are only able to harvest 44 per cent of the organs. That's a substantial loss of 56 per cent among the donors when it's gone for the harvest. Can you underline what is the major factor that we lose that amount of organs?

Ms. VanDeurzen: — I should clarify. That was the outcome of the medical records review that we did in southern Alberta — not Saskatchewan — in southern Alberta in the late '90s. So just to be clear about that. We don't know what it is in Saskatchewan because we haven't done that review. But when we did that review in southern Alberta, it was pretty consistent with the reviews that had been done all over in North America, including some other provinces — not Saskatchewan — and some other states. So it was interesting, and I bring up that process because it aligns with accountability and it aligns with understanding where are the barriers.

Are we losing donors because they don't consent? If that's the reason, then we know our strategies should be really targeted and zeroed in on processes to improve consent. If, however, the barriers are because organ donors are not identified as potential donors in the emergency room, and they're not brought forward even though there's no possibility of saving their life, that's recognized and they're not identified as a potential organ donor and then are not brought forward, that's a failure.

There could be failures in various steps. There's about seven or eight steps in the whole donation process. Any one of those steps could be a place where there's a barrier, a failure occurs. You really want to understand — and in each hospital, in each place it could be different — and you really want to understand, not to blame, but to understand how we need to tweak this here, or where a weakness is, or a possibility for improvement here in this particular location, usually through education of the system, of the team, putting another resource in place.

So the more you know that, the more you can target the resources to improve exactly where the failure to maximize is. Without doing that, we're guessing. And that always leads us to things like registries and presumed consent. Again I emphasize those two solutions are based on something that may not be the biggest problem, which is consent, but that's what they're designed to improve. All the resources go to that when really we have a whole system that needs to be resourced and funded where some of the improvements really could be made. Does that make sense?

Mr. Fiaz: — Yes, correct. Thanks. Mr. Chair, I'll ask one more question, please. You just mentioned that there's a maximum cost available to the donors if a donor is from outside of the country or outside of the province. Do you have that chart for the price of the income support if you can table, please?

Ms. VanDeurzen: — Yes, we will be able to table that with you. My colleague is with me; she administers the program. I know she's chomping at the bit, but we can send that to you. That's no problem at all.

Mr. Fiaz: — Good. Thank you.

The Chair: — Excellent. Thank you very much. Seeing there's no more questions, we'll take a brief recess while we get ready for our next presentation.

[The committee recessed for a period of time.]

[11:15]

The Chair: — Well good morning. We're back at it. Our next presenter is Ms. Sherry Duncan. I'd like to welcome you to the committee today. Before you begin your presentation, if you could introduce yourself, and if you're speaking on behalf of an organization, please state your position within that organization.

If you have a written submission, please advise that you'd like to table the submission. Then once this occurs, your submission will be available to the public. You've heard this several times: electronic copies of the tabled submissions will be available on the committee's website.

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

Our agenda allows for a 30-minute presentation, followed by a 15-minute question-and-answer period. So, ma'am, if you could please begin.

Presenter: Sherry Duncan

Ms. Duncan: — Thank you. I thank the committee for allowing me to speak today. I believe that these hearings on organ donation, there is a great potential to direct the future of organ donation in Saskatchewan, and it really means a lot to me.

My name is Sherry Duncan. At the age of 34, within six weeks of the birth of my second daughter, I was diagnosed with primary pulmonary hypertension. At that time, 24 years ago, there were no drugs or treatments to extend my life, and the only way to save my life was to undergo a heart-double lung transplant. Within weeks of being diagnosed and placed on a transplant waiting list in London, Ontario — at that time, it was the leading centre for transplantation — that's where I was sent for transplantation.

The diagnosis was a devastating shock to myself, my husband, and to all our family members. I had just given birth and I was told I was dying. It was a very surreal experience. The pregnancy and the disease had exasperated my body. My health rapidly declined, with regular hospital stays for heart failure. To walk into my house required that I walk up a landing of three steps, and this was like climbing a mountain.

My health declined to the point where I could no longer pick up my newborn daughter, and I would sit and watch her and cry. And I was blue, literally and figuratively blue. I have a rare blood type and although placed on emergency waiting lists, I was told I was third on the list. All I could do was wait, and things looked very bleak. My chance of surviving was dependent on a chain of events and, ultimately, a gift of organ donation from a grieving family.

I was one of the lucky ones. I only waited five months until I got a call in the middle of the night to come to London. I was so shocked when they initially called me that I told the transplant coordinator that I was feeling a little bit better and maybe I could wait a while. And when I got off the phone, my husband said, what are you doing? And I quickly called them back and said that I would accept the organs.

I was flown by air ambulance to London and transplanted on July 21st, 1992. At that time I received my heart-double lung transplant. When I woke up afterwards, my husband said the sweetest words to me I've ever heard in my whole life: you are so pink.

One of my goals during rehab after the transplant was to be able to hold my baby when I was reunited with her. So the physiotherapist, along with a few of my family supporters, had me carry weights up and down the hallway with a home-drawn picture of a baby taped to the weights. I must have looked really funny walking up and down the halls with these weights. But I met my goal, and when I was reunited with my baby, who I had not seen for two and a half months, I was easily able to hold her and hug her. Out of such a situation have come some of the greatest and most wonderful moments of my life.

The transplant world was a much different place 24 years ago when I started this journey. I had to carry a beeper. I don't know if people even know what beepers are anymore. It was uncommon for people to move. It was not uncommon for people to move from their home province to wait near the transplant centre to receive the specialized care they needed at great personal and family expense. Some even moved in hope that somehow being close to the centre would increase their chances of transplant. Hospital stays were long after transplantation. I broke a record at the time for the shortest stay, post-surgery, and that was 45 days.

Every transplant person was given almost the same drug regime due to limited transplant drugs. Transplanted people were encouraged to wear surgical masks in public, and a lot of people were told, out of fear of infection, especially lung recipients were told not to return to work. At that time the Saskatchewan Transplant Program had just started and had, I believe, two or three staff. There were few support groups and resources to help with adjustment after transplant and, in general, doctor's awareness of the specialized need of people with transplant with suppressed immune systems was lacking.

I had a couple of hospitalizations in the early years where doctors tried to take me off my immunosuppressant drugs, and I quickly learned how to be my own best advocate. Organ donation rates were very low then and not keeping up with demand.

Now, 24 years later, I look back and many things have changed a lot. If I were to develop my disease today, I would be treated with new drugs that would extend my life, putting transplant off for years. The science of transplantation and variety of drug treatment regimes has increased dramatically since I was first transplanted, and I have only benefited from it.

I would most likely be referred to Edmonton for transplant now, but would have a lot of assistance from the staff at the Saskatchewan Transplant Program in terms of preparation and resources and follow-up. I could seek out and find other recipients to talk to. I would be encouraged to return and thrive at work. I would have a specialized transplant physician following me in Saskatoon, saving me travel costs, expenses, and addressing my needs.

[11:30]

Many things have changed. The only thing I really haven't seen change are the low organ donation rates over the years. I do really like the word "culture" that has been used by other presenters. I like to think that I've seen an improvement in general public awareness of organ donation over the years.

There's always room for continuing awareness campaigns and public education to develop this culture.

I do support school programs. There are inroads being met. There are two members of the Canadian Transplant Association in Saskatchewan who have been working with Dr. Moser who presented yesterday with the Saskatchewan Transplant Program. And members of the Catholic school system have just gotten approval within the Catholic school system to teach high school students in a program called One Life . . . Many Gifts. The curriculum will be written and taught in grades 10 and 11 Christian ethics for every school in Saskatchewan. This is a huge accomplishment and something that's been talked about for many years. I think that they'll be starting this in 2017.

I have been involved over the years in quite a bit of organ donation campaigns and education campaigns. One of the most rewarding opportunities I ever had was speaking to intensive care staff at their coffee breaks at St. Paul's and RUH [Royal University Hospital] hospitals where a group of us could share our stories and simply say, thank you for the asking. The response we got from the intensivists that we talked to were . . . They see many patients come through the hospital, but they're all ill. They're all sick; they're all in terrible shape. And to see us afterward, the thriving, healthy people after transplants was very rewarding to them, and they commented a lot on that.

I am an advocate for presumed consent in Saskatchewan and Canada. Although after hearing all the presentations the last couple of days, I do think more focus should be put on our health care system and educating the doctors and nurses who are taking part in organ donation. I do support presumed consent in a way that when a family is faced with a tragic situation, it takes the burden off decision making. But a system procuring organs is only as good as the culture of the system that is doing it, and potential donors are lost in Saskatchewan.

Before attending the hearings in Saskatoon yesterday I wanted to advocate for more training within the health system and at the university levels. I came upon a very in-depth written paper entitled, *Organ and Tissue Donation in Canadian Undergraduate Medical Education*, which has a comprehensive, well-written description on training students at the pre-clinical level of education. In Spain, donor rates shot up when critical care specialists were specially trained. They found success was largely about approach with a very well-trained doctor who could detect a potential donor and approach the family.

When I heard the presentations by the Saskatchewan Transplant Program and Dr. Fenton, who are in the system, I felt a lot of what they had to say made sense. Given that a mandatory referral system is implemented in Saskatchewan, trained donor physicians can gradually train teams in all the health regions in Saskatchewan that have an intensive care unit. I would envision these teams consisting of doctors, nurses, nurse practitioners and social workers, depending on the community and the health region. In the training sessions I would see input from individual donor families and recipients of transplants to illustrate the actual outcomes for people that have been through this so that health care professionals can see and meet the real people affected by this and dispel some of the myths.

I urge you to seriously consider the recommendations of the Saskatchewan Transplant Program and many of the other speakers that have spoken today and yesterday.

In conclusion, I'm here today to honour the gift of transplant. I am alive but through a chain of events and ultimately a gift of organ donation from a grieving family. I only wish that the chain of events to result in better outcomes and increases in organ donation. I have the privilege now to say that I believe I'm one of the longest surviving heart-double lung transplants in Canada, that was transplanted in Canada. And what has that meant? I'm a living example that organ donation works.

More importantly to me, it means that I got to hold my baby again. It means that I got to love that baby and nurture that baby. I got to be a mother to my two wonderful daughters and watch them grow up. Two years ago I got to hold another baby, my beautiful first granddaughter, and I held her with ease and tears of joy dripped down my still-pink cheeks. Thank you.

The Chair: — Thank you very much for your submission. Just before we jump into questions, I want to table HUS 29-28 Sherry Duncan: Submission regarding organ donation inquiry. And we have Ms. Carr up.

Ms. Carr: — Thank you very much. Thank you very much for your story and giving us some insight on what it was like for organ donation years ago and how we have come along. And I appreciate the fact that you sat through all these hearings and listened to all of the different presenters as some of us have. And just being able to focus on what's important, getting the system working better, and all of the components that go into it, I just want to thank you for you expressing that view after listening to them. It helps us decide as legislators what direction we want to go because it's so important. Thank you.

Ms. Duncan: — Thank you.

The Chair: — Ms. Chartier.

Ms. Chartier: — Thank you very much for your story. I know that's brought tears to my eyes, particularly your last . . . Being able to hold your granddaughter must be a really amazing feeling.

Ms. Duncan: — Yes.

Ms. Chartier: — I just wanted to ask you, I had heard briefly . . . We haven't heard about this in the committee, but the Catholic school program, I had heard from someone else that it's only been piloted in the Catholic system. I understand it was Sheila Chad, a former principal, and Dr. Moser and a few others who've put it together. But you believe that it's gone a little bit further than that?

Ms. Duncan: — I believe it has. I can certainly check that information because I have regular contact with a couple of people on the committee, so I can easily check that.

Ms. Chartier: — Okay. I'm wondering if we could direct our Clerk to seek out a little bit more information on this particular program. And I actually, I can get Sheila Chad's contact information, or contacting the transplant program and speaking to Dr. Moser as well. But it would be great to have a little bit more information on this program as well. Thank you.

The Chair: — Seeing no other questions, I wish to thank you for that story too. So it does bring insight into it, and just thank you very much. So seeing that there are no more further questions, that concludes our committee meeting for today. I would now ask for a motion to adjourn. Ms. Carr.

This committee stands adjourned to the call of the Chair.

[The committee adjourned at 11:39.]