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Official Report of Debates (Hansard)

Thursday 19 April 2007

Journal des débats (Hansard)

Jeudi 19 avril 2007

**Standing committee on
the Legislative Assembly**

Organ and Tissue Donation
Mandatory Declaration Act, 2007

**Comité permanent de
l'Assemblée législative**

Loi de 2007 exigeant
une déclaration au sujet
du don d'organes et de tissu

Chair: Ted McMeekin
Clerk: Tonia Grannum

Président : Ted McMeekin
Greffière : Tonia Grannum

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LEGISLATIVE ASSEMBLY OF ONTARIO

**STANDING COMMITTEE ON
THE LEGISLATIVE ASSEMBLY**

Thursday 19 April 2007

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**COMITÉ PERMANENT DE
L'ASSEMBLÉE LÉGISLATIVE**

Jeudi 19 avril 2007

The committee met at 1601 in committee room 1.

SUBCOMMITTEE REPORT

The Chair (Mr. Ted McMeekin): Members of the committee, thank you all for coming, and to our guests, welcome. We'll begin with a report of the subcommittee. Is there a mover?

Ms. Jennifer F. Mossop (Stoney Creek): Your subcommittee met on Monday, April 2, 2007, to consider the method of proceeding on Bill 67, An Act to amend various Acts to require a declaration with respect to the donation of organs and tissue on death (Mr. Klees); Bill 164, An Act to amend the Consumer Protection Act, 2002, the Environmental Protection Act and the Occupational Health and Safety Act (Mr. Tabuns); and Bill 161, An Act respecting employment agencies (Mr. Dhillon), and recommends the following:

(1) That the committee meet for public hearings at Queen's Park on Bill 67 the afternoon of Thursday, April 19, 2007, and meet for clause-by-clause consideration the afternoon of Thursday, April 26, 2007.

(2) That the committee meet for public hearings at Queen's Park on Bill 164 the morning of Thursday, April 26, 2007, and meet for clause-by-clause consideration the afternoon of Thursday, May 3, 2007.

(3) That the committee meet for public hearings at Queen's Park on Bill 161 the morning of Thursday, May 3, 2007, and meet for clause-by-clause consideration the afternoon of Thursday, May 10, 2007.

(4) That when the committee meets in the morning, it meet from 10 a.m. to 12 p.m., pursuant to the order of the House, and when the committee meets in the afternoon, it meet from 4 p.m. to 6 p.m., subject to change and witness demand.

(5) That the clerk of the committee place one advertisement for the three private members' public bills for one day in all the English dailies, the one French daily and in the York regional papers.

(6) That the clerk of the committee post information regarding public hearings on Bills 67, 161 and 164 on the Ontario parliamentary channel and the committee's website.

(7) That interested parties who wish to be considered to make an oral presentation on Bill 67 contact the clerk of the committee by 5 p.m. on Tuesday, April 17, 2007.

(8) That interested parties who wish to be considered to make an oral presentation on Bill 164 contact the clerk of the committee by 5 p.m. on Tuesday, April 24, 2007.

(9) That interested parties who wish to be considered to make an oral presentation on Bill 161 contact the clerk of the committee by 5 p.m. on Tuesday, May 1, 2007.

(10) That the sponsors of each of the three private members' public bills be permitted to make a five-minute opening statement at the outset of public hearings on their respective bills.

(11) That all witnesses be offered a maximum of 10 minutes for their presentation.

(12) That the deadline for written submissions on the three private members' public bills be 5 p.m. on the day of public hearings for each bill.

(13) That for administrative purposes, proposed amendments should be filed with the clerk of the committee by 6 p.m. on Tuesday, April 24, 2007, for Bill 67; by 6 p.m. on Tuesday, May 1, 2007, for Bill 164; and by 6 p.m. on Tuesday, May 8, 2007, for Bill 161.

(14) That the research officer provide the committee with background research on mandatory declarations in other jurisdictions with respect to Bill 67, and background research on comparable legislation in the European Union, Vermont and California and other jurisdictions with respect to Bill 164.

(15) That the research officer provide the committee with a summary of public hearings by 5 p.m. on the Monday of the week during which clause-by-clause consideration will take place for each of the three private members' public bills.

(16) That the clerk of the committee, in consultation with the Chair, be authorized prior to the adoption of the report of the subcommittee to commence making any preliminary arrangements necessary to facilitate the committee's proceedings.

The Chair: Move seconded? All in favour? Carried.

**ORGAN AND TISSUE DONATION
MANDATORY DECLARATION ACT, 2007**
**LOI DE 2007 EXIGEANT
UNE DÉCLARATION AU SUJET
DU DON D'ORGANES ET DE TISSU**

Consideration of Bill 67, An Act to amend various Acts to require a declaration with respect to the donation of organs and tissue on death / Projet de loi 67, Loi

modifiant diverses lois pour exiger que soit faite une déclaration au sujet du don d'organes et de tissu au moment du décès.

The Chair: We'll move to an opening statement by the sponsor of this bill, Frank Klees.

Mr. Frank Klees (Oak Ridges): At the outset, I want to take this opportunity to thank my colleagues for giving their consent to the all-party agreement to bring this private member's bill forward for public hearings. This is an important next step for this bill, which was unanimously supported during second reading on March 30, 2006.

I also want to thank members of the public for their expressed interest in the broader issue of organ donation and this bill specifically. That interest was expressed over the last number of months through numerous petitions that were read into the record by members from all parties. Their voices, through those petitions, are heard at this committee as well.

I want to thank also the many Ontarians who submitted their comments through e-mails and letters over the last number of months, especially those who will be appearing here today. We look forward to their advice, their input and their clarification.

I want to make reference to one specific letter that I received from Linda MacGregor, the president, and Elaine Harvey, the chair of the education standing committee of the Canadian Federation of University Women, Ontario Council. In that letter they pointed out something that, quite frankly, I as the drafter of the bill had missed. That was, while the intent was very clearly stated—that individuals would be given an opportunity to express their wishes, yes, no or undecided—they pointed out that the “undecided” reference was not specifically referenced in the legislation. They felt that it would be important to incorporate that in the legislation. I just want to give notice at the very outset that it's my intention, when we go into clause-by-clause, that I will be moving an amendment to incorporate that very specific term so that it's very clear that we want to ensure that individuals are given the opportunity to consider the important issue of organ donation, that no one intends to force anyone into making a decision, thereby leaving the “undecided” option available to individuals as an expression of their position on this.

I also want to take this opportunity to thank the Citizens Panel on Increasing Organ Donations who, under the leadership of Dr. Ted Broadway, travelled the province over the last number of months soliciting input on the issue of organ donation and prepared a comprehensive report that made some 26 recommendations to the government. That report was formally released this morning, and I'm pleased to report to the committee that the panel very expressly endorsed the provisions proposed in Bill 67. Dr. Broadway expressed very clearly in his remarks this morning that he would want to see the day when every Ontarian is required to make a declaration concerning organ donation on their health card or their driver's licence and that those declarations,

in his words, would be “yes,” “no” or “undecided.” That, of course, is precisely what Bill 67 does.

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I'd like to acknowledge as well Mr. George Marcello, present with us today, himself an organ recipient and an activist for organ donation. Mr. Marcello has travelled the world in support of this issue and has headed up and organized—he's the charter founder of an organization called Step by Step. He's doing incredible work to raise awareness of organ donation, not only here in Ontario but internationally.

I would also like to read into the record, if I could, a statement by the Ontario Medical Association that they issued this morning:

“The Ontario Medical Association ... strongly supports increased awareness and education to improve organ donation rates in the province of Ontario. Today, Bill 67, Organ and Tissue Donation Mandatory Declaration Act, is being considered by the standing committee of the Legislative Assembly. The bill proposes that Ontarians over the age of 16 be required to fill out their donor cards in order to obtain a driver's licence or health card. Ontario's doctors believe the steps outlined in the bill will help improve donation rates, and we encourage all parties to work together to implement the bill.”

I want to, finally, read into the record one of the letters that I received from Mr. Sam Marcello, who is a brother of George. He states that he would have liked to be here himself, but he wanted to have this noted:

“Please be advised” that “I am unable to attend the public hearings on April 19 ... on the issue of organ donation. I would like to make my comment on this issue. I believe that this Bill 67 will save more Ontarians' lives as there will be more individuals donating their organs. Please accept this request to have the bill become law.”

We look forward to hearing the submissions today. Of course, the public understands that, based on the submissions we receive, we as a committee will take into consideration any advice we might have to improve the bill, to perhaps make some adjustments in the fine details of the wording, and then the bill would come to clause-by-clause next week for final consideration. The hope then would be that the government would see fit to call it back into the Legislature for final approval.

In summary, by the very fact that it is a mere administrative measure, that it is very straightforward, that it does not force the hand of anyone but simply creates the opportunity for us in this province to raise the awareness of organ donation, I'm hopeful that I'll have the support, not only of this committee but of the Legislative Assembly, in enacting this bill.

The Chair: Thank you very much, Mr. Klees. As Mr. Klees has outlined, we intend to hear from public presenters this afternoon. Then, next Thursday morning, I believe, we're into clause-by-clause.

ONTARIO BAR ASSOCIATION

The Chair: Members of the committee, we have a list of those who have indicated a desire to speak. Appar-

ently, the 4 o'clock and the 4:10, namely Peter Casey and Angela Casey and the Ontario Medical Association, have both cancelled. Your agenda should show that.

We'll ask if the 4:20 presenter, the Ontario Bar Association, is here. Welcome, ladies. If you would state your names for the record, then I can just explain. You have 10 minutes to make your presentation. Should your presentation fall short of the 10 minutes, no problem. That will allow committee members time for questions.

Ms. Jasmine Ghosn: Good afternoon. Thank you for allowing us this opportunity. My name is Jasmine Ghosn. I am the chair of the Ontario Bar Association, health law section. With me is Mary Jane Dykeman, who is a member of our executive.

Several months ago, it came to our attention that there were actually four bills in front of the Legislature on organ donation and that the ministry had struck a citizens' panel on organ donation. As a result of this interest, we struck a committee of lawyers who practise in the area of health law to review this issue of organ donation.

Mary Jane Dykeman, who is on the committee, is going to present some of the issues that we have identified and would like to bring to your attention.

Just a little background about the health law section at the Ontario Bar Association: We have 300 members, who focus their practices on health law. We are 300 of 17,000 lawyers in the province.

We're very pleased to have this opportunity to represent the Ontario Bar Association here today.

Ms. Mary Jane Dykeman: It's a wonderful opportunity and a great topic, both from a legal perspective and a social policy perspective—obviously, that's why all of you are here.

Just by way of an anecdote, many years ago, before I started law school, I worked in an administrative capacity for the multiple organ retrieval and exchange program in Ontario, the predecessor group to the existing Trillium Gift of Life Network. In that capacity, I had to field hundreds and hundreds of calls from individuals in the public looking for information about organ donation. Those were in my early formative years of really looking at allocation of scarce resources, biomedical and ethical issues and the like—and part of the reason I went to law school, frankly.

Day to day, many of the 300-plus members of the health law executive at the Ontario Bar Association are dealing with consent-to-treatment issues. Obviously, there's some parallel.

I would certainly say that from the perspective of having heard from many of those members of the public, there's always the need for education, which is part of the mandate of the Trillium Gift of Life Network—and always looking at ways to increase the number of donations.

That's nigh on 20 years ago, and there has been a lot of progress since. As we sit here today with this bill—I think Mr. Klees characterized it as an opportunity. From our perspective as health lawyers, I think that's exactly what it is.

I don't think that we see any inherent impediment—it would be hard to suggest that there is—in the framework that has been set out here. Clearly, they are straightforward amendments to a couple of pieces of legislation from the point of view of families and people looking ahead to the possibility that they should ever be in that circumstance. It only makes sense that a person going in for a health card or going for a driver's licence could be asked that question reasonably.

As you're aware, there are many other proposals, internationally, nationally and in Ontario, that receive great scrutiny.

What we will say is that as a non-invasive conversation starter, this is a great step.

One of the things that I used to hear when people called was that they wanted to know what the status of this medical directive was—if they signed something, what would happen? We always encouraged them very strongly to make those wishes known to family. One of the things that people would worry about, of course, was: Where do you find that piece of paper?

In fact, when I raised this with family members yesterday—they were just asking what my day entailed, and I mentioned that I was coming here to speak to this committee—two people started rooting around, looking through their wallets, saying, "Did I ever sign one? Well, you know what my wishes are, so that's fine."

This is one way of having that conversation out front. In conjunction with any educational initiatives that are also put forward as part of the broader framework, it's probably a very good, coordinated approach.

In short, we have no real objections to it. I think we're very strongly supportive of it.

Probably the only question we have—and we did supply a fairly lengthy submission, which would not be a surprise, really, that flows somewhat out of the work that we did on the four proposed bills and provides a lot of detail. But to narrow the focus to Bill 67 and the work that's being looked at here, I think it's the question of the registry and how that might work, and also, as part of the educational initiative, how do you put it forward in a manner that is not intrusive, that spurs the conversation and the careful consideration of a person who might want to make that decision; and also the reflection that however it's presented, that it doesn't coerce the person or have—of course, it's not meant to coerce the person, but not have the perception of coercion, or of judgment, for that matter.

1620

I think there is some question in terms of how the registry would work, how we track the decisions that people make and how we would have a mechanism in place to really identify the point at which a person withdraws consent. Again, working in areas where we're dealing with health care consent, it's a constant challenge and I'll say opportunity—I'll use Mr. Klees's words—to ensure that we track patient consents for treatment properly. I think the same goes for this framework.

So those are the things we'd like to know more about. We're certainly happy to answer any questions in the short time that we have. Thank you.

The Chair: Thank you. We have about four minutes, so why don't we take a couple of minutes each. We'll start with you, Mr. Klees.

Mr. Klees: I appreciate your submission today. First of all, your reference to a registry system is right on the mark, and of course this bill doesn't deal with that. It is contemplated that that will in fact be an important part of the overall system that we look to the government to implement, and the panel made specific reference to that. So we're looking forward to that.

You have raised a legal consideration with regard to the issue of the withdrawal of the declaration. Do you have any specific recommendations that you could make by way of an amendment to clarify that aspect of it?

Ms. Ghosn: It might be helpful to include, perhaps on the form the person fills out or even on the card that's eventually issued, that in the event an individual at a later date would like to withdraw their consent, they can dial a 1-800 number or somehow get in touch with an authority that would quickly take that information. It's helpful in several ways. It might even be that the 1-800 number is also the number for people to give consent; maybe they don't drive, maybe they don't have an opportunity to fill out one of these forms. So it's all connected to the same registry system. That was part of the recommendation.

We know the Trillium Gift of Life Network is going to be heavily involved in organ donation, and they may be the applicable entity to assume responsibility for coordinating a registry system. Our recommendation would be that this withdrawal of the consent would be tied in to that entity.

Mr. Klees: Thank you very much.

Mr. Peter Kormos (Niagara Centre): I quickly read your submission, your written material. I urge people—I don't know if there are copies of it there or not. It's a very valuable and concise synopsis of some of the leading literature, including, most notably, comments on the cultural aspects of it and our need to recognize cultural differences. Mind you, I suppose I'm a cultural revolutionary. I want to change the culture around organ donation. I mean, I just don't feel possessive about mine at all. I suppose while I'm alive I have regard for them being kept intact, but once I'm gone, as I have told so many people—I've got two things: I've got a 1994 Chevy pickup and my organs. Once I'm dead, I have no use for either of them. Anybody who wants or needs them, come and get them.

Look, here's the bill. It's consistent with the primary—one of the primary recommendations of the blue ribbon panel was, let's get rolling on this. It's a modest proposal in the total scheme of things. You talk about a registry. Heck, if cops can CPIC my driver's licence number—K66176253521007—and find out all sorts of things, why can't that similarly be the database for determining whether or not my licence says go to town when it comes to harvesting or salvaging or saving lives?

Ms. Ghosn: If I can just respond to the cultural issues, I think it would be helpful also in the application process to have either web links or resources where people can go if they have questions or they want more information on organ donation. The process of filling out an application form is very technical—fill in your name and address; do you declare, yes/no? It may be helpful to have a reference that people can go to for additional information.

The Chair: A question on the government side?

Mr. Kuldip Kular (Bramalea–Gore–Malton–Springdale): First of all, thank you very much, both of you, for coming forward before the committee to give your long submission.

Right now, people sign their driver's licence for their organ donation. If one of the family members or next of kin is trying to change their decision—the question I have is, should that tool be changed or not?

Ms. Dykeman: Speaking from a hospital perspective, and not on behalf of any single hospital, what we hear—and even in my experience some years ago—is that the physicians and the hospital generally will not override the wishes of a grieving family. In terms of whether one could make that medical directive enforceable, to that extent it's probably possible legally and legislatively, but it certainly is a much stronger step—again, maybe part of the education.

The Chair: Thank you very much. We appreciate your presentations.

KIDNEY FOUNDATION OF CANADA

The Chair: Is there someone from the Kidney Foundation with us? Again, for the record, please tell us who you are, and once you've done that, we would invite you to speak for up to 10 minutes.

Ms. Janet Bick: My name is Janet Bick. I am the director of government and professional relations for the Kidney Foundation of Canada.

Joining me is Wayne Sampson, a kidney transplant recipient and active volunteer with the foundation.

First of all, we would just like to congratulate Mr. Klees for his perseverance in bringing Bill 67 to this point and to thank the committee members for this opportunity to comment on the bill.

We will try to be brief and leave some time to respond to questions.

To begin, Wayne will share with you what a kidney transplant has meant to him and his family.

Mr. Wayne Sampson: Thank you very much, first of all, for letting me present.

I've got a sheet here and I'm probably going to follow it the best I can, but I'm not used to speaking in this manner, so I'd rather just go mainly by memory.

In 1980, I was diagnosed with polycystic kidney disease, which is a hereditary disease given to me through my family, mainly my mother. At the same time, I was born with one kidney, but I didn't know that for

many years. From that time until 2002, I lived a normal life. I had no real health issues.

In early 2002, I was referred to a pre-dialysis clinic, which meant I would be put on dialysis eventually, at Lakeridge Health in Whitby.

My health continued to decline and my energy level became lower and lower. I was unable to continue working full-time and was forced into early retirement at the age of 55. The frustration of being unable to keep my normal lifestyle was very hard to deal with. I tried to push myself every day, but I spent the rest of the time sleeping.

When I started on dialysis, I felt better. It's not exactly administered as a pill, but it was a great pill. I felt better. I was still tired. My daily activities were very challenging, and I had some issues.

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In July 2005, I received a kidney transplant. The donor of my new kidney was one of my daughters. It was a live donor. She and I are both doing wonderfully after the procedures. There isn't a day that passes that I don't appreciate my new gift of life. I can only wish that the people waiting for a transplant—I hope you have that information in front of you; if you don't, we can certainly get it for you—could some day experience what my family and myself have been able to enjoy since July 2005. Thank you.

Ms. Bick: As Wayne has told you, kidney transplants offer the best chance for a return to normal life. Kidney transplants save lives, but last year 41 people in Ontario died waiting for one. Ontario has the second-longest wait time for a kidney transplant in Canada. The median wait time for a first adult kidney transplant between 2002 and 2004 was 4.5 years. Some have been waiting for as long as 10 years. In 2006, there were 1,194 people waiting for a kidney transplant in Ontario, and only 498 were performed. That's less than half the list, and the list grows each year.

The Kidney Foundation supports Bill 67's desired outcome of increasing the availability of organs and saving lives. As we note in our submission, organ donation is a complex, multi-faceted process influenced by a wide variety of activities occurring at the individual, institutional and societal level.

Bill 67 offers Ontarians an important opportunity to register their wishes regarding organ donation. However, checking off a box on a health card or driver's licence is only a first step. The importance of individuals talking to their families—we heard this from the previous presenters—and making their wishes clear cannot be overstated. In the unfortunate circumstance where someone has suffered a traumatic injury or medical event and is identified as a potential donor, it is the next of kin who will be approached to give consent.

Studies have shown that families who are not aware of their loved one's wishes are just as likely to withhold consent as to give it. It is therefore imperative that in the implementation of the provisions of Bill 67, initiatives be put in place to ensure that the public understands the

need to discuss their wishes with their families to minimize uncertainty and possible conflict at the time of death. The development of a province-wide public education social marketing campaign with multiple stakeholder input is required. The campaign should be ongoing and promote clearly articulated, consistent messages.

We all know what drinking and driving campaign messages have done. We all know what anti-smoking campaigns have done. It's time to do this for organ donation.

The programs should be designed for implementation by local constituencies and the ministries of transportation and health and long-term care, which are responsible for drivers' licences and health cards, respectively. The key messages should focus on the benefits of organ donation and transplantation as well as the importance of sharing your decision to donate with your family. An ongoing and sustainable campaign promoting clear, concrete actions is needed to complement the systemic improvements already achieved by the Trillium Gift of Life Network to convert positive intentions into increased donors.

Donor families uniformly report that agreeing to donation gave comfort and meaning to the sudden traumatic death of a loved one. Every Ontarian who wants to be an organ donor, if such circumstances arise, should know that their wishes would be respected.

The Chair: Thank you very much. We have about four minutes or so, so we'll try a minute each, because they tend to go a bit over. We'll begin with you, Mr. Klees.

Mr. Klees: Thank you again so much for your submission and for the good work that you do. Mr. Sampson, the fact that you're testifying to how a transplant has in fact saved your life I think helps us to better understand the urgency of being able to make this possible for more people. The waiting list for organ transplants is, I think, in many ways the silent waiting list in this province. We talk a lot about hip and knee replacements and other waiting lists, but we very seldom talk about this, yet there are people in agony day after day and one person dies every three days in this province waiting for a transplant.

I thank you for your good work and also for your reference to the importance of education. As you know, the bill is intended to do exactly that by, on an ongoing basis, reminding people every time their renewal comes up that they have to confront this issue. I think what you're saying is that, in addition to simply making this part of the application, there should be a way that we can supplement that requirement with some additional information that will make people feel more comfortable about the act of committing to being an organ donor. Perhaps we can get some advice from you on exactly what that should look like.

Ms. Bick: We know that a tremendous amount of time and people's energy over the last probably 15 to 20 years has gone into looking at the barriers to organ donation. We know that amongst the public there are often so-called myths that people are concerned about. I think

materials and programs really are needed that can address some of the concerns, along with—this morning, the panel on organ donation in its report does also talk about religious differences and cultural differences. I think those need to be respected and explained. I don't think that enough ongoing attention has been given in a public fashion to making the public aware of all of these issues. Next week is National Organ and Tissue Donor Awareness Week—it's a mouthful; NOTDAW for short—and that's once a year. We need to be hearing organ donation messages every week.

Mr. Klees: Thank you.

The Chair: Mr. Kormos?

Mr. Kormos: Thank you kindly, both of you. You've raised some issues that compel me to request of our legislative research person—one, I'd like to know—obviously we're limited in what can be donated by a living donor, because it's got to be those types of organs like kidneys, where God gave us two rather than just one.

Ms. Bick: At least. Some people have more.

Mr. Kormos: Of kidney donations, can you get some numbers for us on how many come from living donors versus non-living donors; and, of the living donors, the nature of the relationship, because I presume there are issues around matching?

Where this takes me to is this: Canadians, I believe, are very generous people. Young Canadians volunteer—we don't have a draft, but they volunteer for the armed services and not only risk but give their lives and are being shipped home, sadly, on a weekly basis. What will it take to make us feel good enough about ensuring someone else lives to be a living donor for an absolute stranger? Do you see what I'm saying?

Ms. Bick: I hear you.

Mr. Kormos: I want to know what we have to do to create a society where a Canadian would be a living donor to someone they had no idea about and maybe never will. That's an admirable goal, it seems to me.

Ms. Bick: I think that's certainly something that people might well like to see happen. Just to answer your research question first, last year approximately 225 living donors provided kidney transplants in Ontario. The relationships are generally family but they are also often a friend, a colleague, that sort of thing. So it doesn't have to be a blood relation.

The issue of what you would call living anonymous donation has certainly been looked at. Currently, there has been a pilot in BC that has gone very quiet, and we're not sure why. But it's certainly an issue that is out there. I think part of the education and part of the other pieces that we're talking about here today might well contribute to that. This one is a little bit more loaded in terms of some of the ethical issues and so on, and maybe there's a need for finding out what the public really thinks of that.

Mr. Kormos: Thank you, ma'am.

The Chair: One minute, Ms. Mossop.

Ms. Mossop: I suppose I just want to support your concept around education and also speak a little bit to Mr. Sampson. Back in 1971, my father died of kidney

disease just short of being put on the table for a very pioneering kidney transplant. I was 10 years old at the time so I wasn't in a position to do what your daughter did, but boy, I'd love to have had that opportunity. My mother subsequently worked for the Kidney Foundation of Canada and with Dr. Cal Stiller in London, at University Hospital, where they started to move those transplants into the successful operations that they now are. I remember going to shopping malls with her when I was a young teenager and trying to convince people to sign these cards. I would always go up to these very nice-looking, elderly ladies who were likely just to say yes because they were sweet. My mother was going up to these young, really tough-looking people like bikers. I said to her afterwards, "Why are you going up to them?" She said, "Well, you know what? With their lifestyle, they're more likely to be candidates to help us out sooner." Maybe that was brash but, boy, you had to get in there and get the job done.

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She also went out to service clubs and helped to educate people. I think the education was really a huge factor. Subsequently, we had the families of living donors stay in our home when they were going through this new operation, and I just want you to know that that discussion is alive and well in all parties. Obviously, you've seen the number of private members' bills that have come forward on this issue, and also the panel the government struck that's been travelling the province to raise awareness, to consult and to get some recommendations as to how best to move forward to make your miracle the miracle we can share with as many people as possible. So thank you for your time here and for sharing your story.

The Chair: Thank you for sharing your story. Ms. Mossop, thank you for sharing yours as well.

HENRY LOWI

The Chair: Mr. Henry Lowi. Did I pronounce that right?

Mr. Henry Lowi: Yes, thank you.

The Chair: Welcome, Mr. Lowi. We know for the record that this is Mr. Henry Lowi. You have 10 minutes, sir.

Mr. Lowi: Thank you very much for permitting me to appear before you today. And thank you to Mr. Klees and to Mr. Kormos for your private members' bills, which I think are excellent initiatives.

In the news recently there's been heightened interest in this issue because of some tragedies, but there's also been heightened awareness, I think, as a result of education and efforts that have been taken and that have been made by groups like the Trillium Gift of Life Network, in which I'm a volunteer. I actually interact very often with the public. I've done this for several hours this week already and there has been a change. I can tell you that in my limited experience, in the last two or three years there's definitely been more awareness of this

issue, and people are more opinionated, which is the important thing, than ever before. I think that the problem, as I'll express in my deputation today, is that the government is lagging way behind in facilitating effective organ donation from willing donors.

Just a little bit about myself: I was diagnosed four years ago with idiopathic pulmonary fibrosis, which is a disease that has no effective treatment and no cure. The mean survival time for IPF patients is 28 months, so I've outlived my best-before date already. Almost all are dead within five years. Thanks to serious lifestyle changes, diet and exercise, I've kept my condition stable, but the expectation is that at some point my condition will suddenly and rapidly deteriorate, and then I'll require a double lung transplant within two to four weeks. Without the transplant, I'll be dead within two months from the moment I begin to decline.

You've heard about the 1,800 people who are on the waiting list, and you've heard about one dying every three days. And you've heard a little bit about, from one of the last speakers, the fact that even when people sign their donor card, if there's a miscommunication or lack of communication between them and their families, then family members in 50% of the cases where people have signed a donor card and the donor card has been found have said, "I don't know. He never talked to us about that, so I really don't know." So that's a structural flaw in the system. In my view, the system is not really a system to facilitate organ donation; it's a minefield to prevent organ donation. I will explain briefly why I think that's the case.

Either I was approached with a card or I wasn't. Either I signed it or I didn't. Either I kept it in my pocket or I forgot it at home. Either I spoke with my family about my wishes or I didn't. Either the card was on me when I was in the traffic accident or it wasn't. Either hospital staff approached my family who were present in the hospital in a sensitive and appropriate manner or they didn't. Either my family was able to deal with their grief or they weren't. In other words, every step of the way is fraught with human error which could prevent my organ from being donated, because it's a system that's based on both random signing or non-signing of cards, no central registry, and dependent on the ultimate consent of surviving family members. Those three factors put healthy organs into the ground. Those are factors that put healthy, useful organs into the ground.

In public opinion surveys that have been done in Ontario, people express willingness to participate in organ donation. People support it. I'm saying that the system is designed to prevent it.

What I think has to be part of the system: The system has to have a registry. You can't do without a registry. There was mention here of an 800 number. There are probably 17 different ways one can express one's wishes on a registry, whether it's an opt-in system or an opt-out system. There has to be a registry.

In my view, the simplest thing to do is to have the registry linked up with the OHIP system. Why? Every

time I access the health system—and it's about three times a week these days: doctor, clinic, hospital—they ask me, "Is this still your number?" "Yes." "Do you still live at 123 Main Street?" "Yes." Every person I interact with is programmed to confirm my address. Why can't that same computer screen program them to ask me, "Are you still a donor or not"? That's all. "Are you still a donor or not"? Couldn't the same pop-up that says "Ask about address" say "Ask: Donor, yes or no? I think technically it would be quite simple, and that's whether you have an opt-in or an opt-out system. You need a registry for both because it has to be simple and transparent to take either step.

Of course, that same registry has to be linked up with the hospital, because in the hospital, when I'm on my deathbed and they're figuring out what to do with me, they're going to look at a few things about me. One of the things they can look at is "Donor, yes; donor, no," and that's a command.

I think it's important that if a person is "Donor, yes," there should be the possibility of family members to override that in some way, an affidavit saying, "He changed his mind last week," that kind of thing. But I don't want the system to be based on mandatory consent of the surviving family. In other words, my decision is a command to the system unless some procedure overrides it that preserves my wishes, ultimately.

That is basically it. I think we have to go toward a presumed consent model. I think that's the fairest and it's the bureaucratically least complicated. It's the least expensive, certainly. I think it would accomplish the wishes of the majority of people in Ontario, while preserving the individual liberty and autonomy to opt out.

The excellent contribution of Bill 67 is that it deals with the front end of the minefield. The front end of the minefield means, "Was I offered a donor card or was I not?"

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Bill 67 says you have to express your wishes, but it doesn't deal with all the problems down the road. We have to deal with those. Thank you.

The Chair: Thank you very much.

JOHN PARISEE

The Chair: Mr. John Parisee? Is that your correct surname, Parisee?

Mr. John Parisee: Parisee.

The Chair: Parisee. Welcome, Mr. Parisee.

Mr. Parisee: Thank you, and it's a privilege to be here, but you might not like to hear what I might have to say because I see some different issues on basic rights under our Charter of Rights.

The Chair: Well, let's find out. You've got 10 minutes.

Mr. Parisee: The basic concern here is that the mandatory, cohesive nature of the proposed amalgamated implementation of amending the Health Insurance Act and the Highway Traffic Act is a clear violation of our

basic human rights in that it implies that the residents of Ontario are the property of the state, and further, that the disposition of the organs of the deceased becomes the purview of the state, i.e., ownership of one's body is now transferred to the province.

This is truly a sad day for all the people of Ontario and implicitly for all Canadians if Bill 67 ever gets passed through the Legislative Assembly as a the private member's bill. Most of us here had grandfathers, fathers and uncles who fought in two world wars, allowing us to enjoy the freedoms and democracy we have today, which we stand to lose by the nature of this bill. We have our soldiers in Afghanistan right now fighting for the rights of Afghan people while ours here in Ontario are slowly, but surely, eroding. Maybe before we send any more troops to go fight over there, they should stop here in Ontario first for the democratic principles and basic human rights we are about to lose under Bill 67.

I would further like to commend Mr. Klees for bringing this important issue to the fore. Most people can empathize with the importance of this issue, and those who are waiting for organ donations so they can have some normalcy returned to their daily lives and reduce the heavy costs to our health care insurance for dialysis and other similar procedures.

A similar bill was brought before the assembly by Mr. Kormos a couple of years ago and was turned down as a rogue bill. Bill 67, as worded, shows clearly that the province is drifting into totalitarian and very non-Canadian solutions in its desire to be politically correct and do what appears to be the right thing.

Bill 67 has not taken into consideration all the mainstream religious faiths such as Jewish, Muslim, Hindu, Jehovah's Witness and many native faiths that believe that on death they must be buried with all their body parts and blood.

Bill 67 does not take into concern people infected with HIV/AIDS or hepatitis A, B and C, who in many cases don't even know they are infected. Then there are those who would not report other STD infections for many personal reasons. This is a preventable epidemic just waiting to happen.

Bill 67 does not take into account the great many people with cancer, not only those who are being or have been treated but those who may be in the early stages and are unaware of their condition. These people are generally not permitted to donate blood, and certainly their organs should not be available for transplantation.

On a more practical level, can someone please tell us why they want to merge parts of the Health Insurance Act with the Highway Traffic Act? Is this designed as a way of letting the health minister get his hands on more money? Look at the billions of dollars the province already hoovers out of the pockets of the public under the Highway Traffic Act from drivers' licence plates, off-road vehicles, fuel taxes and other hidden taxes and fees. We pay handsomely for this privilege, as it is. What will it cost us after Bill 67 is enacted?

Please consider that mandatory implementation of Bill 67 will lead to mandatory medical certificates. How else

can you ensure that the organs are fit for donation? How often will these medical certificates require renewal? I am certain that there is a cost involved here. Will this be added to the burden of OHIP or will this be added to the expense of anybody needing a driver's licence? Remember that drivers' licences are not a frill, but in most cases needed for work. This too will invite fraud by people desperate enough to get phony papers.

For many years now, we have been getting our organ donor renewal card with our driver's licence. As I explained above, there are many reasons why I don't sign it, not just apathy. For the same reason, the negative option has been rejected.

On a personal note, I never signed mine for a good reason. In 1965, I was involved in a serious car accident. I had the gift of donated blood. It kept me alive, and I am grateful. But as a result, I contracted hepatitis. As none of my organs are of any use for donation, it would not be ethical, and I would certainly not want to be responsible for giving it to somebody else. They would have a whole new set of health problems which I would not wish on my worst enemies. So if I was involved in a car accident or any other sort of accident that is going to be blended or merged or amended or combined or harmonized or whatever with the Health Insurance Act and the Highway Traffic Act, I would not want to be drained or dissected for any reason at all.

I know that under our Charter of Rights and Freedoms, we have no property rights. With Bill 67, is the province of Ontario extending its dominion over our most sacred possession, our body? Is Bill 67 saying that we have no rights to our own body parts? We will have to ask Mr. Harper to hurry up on one of the promises he made to give us our most fundamental property rights back. Our body parts are God-given possessions and not yet another means to a revenue stream for the province.

We've talked about how bad this plan is. Now let's talk about some other avenues that should be looked at seriously and put into effect by the health care act and the Minister of Health. They have to come up with a better solution for people who are waiting for transplants and get all-party agreement, like Mr. Kim Craitor did for grandparents' rights. Everybody will have to sit down, take a serious look and then pass a bill that will benefit everyone concerned on how organ transplants should compassionately be done here in Ontario. This could serve as a template for the rest of Canada.

(1) The Minister of Health should have a separate fund put in place to help a person who donates an organ, whether it's a brother, sister, cousin, friend or whoever, allowing them to take time off work, offsetting wages and the cost of medication required prior to the operation. This should be done for as long as needed after the surgery, until the doctor says they can return to normal activities. There should be a special tax incentive program in place for employers of organ donors to help cover the cost impact. There should be recognition for the compassion shown by the donor and those who made his or her donation possible. These are just the little acts

of appreciation that will encourage people to step forward and cut out those stumbling blocks that make people reluctant to help.

(2) This point may be a controversial one, but, in the big picture, it must be examined, as family and friends cannot supply the number of donations required: the purchase of organs from a compatible living provider. Suitable safeguards must be included to prevent abuse.

(a) The person buying the organ must cover all costs for themselves and the provider.

(b) The provider must have been a resident of Ontario for a minimum of five years and must supply all the verifiable records to prove that he was not brought in just for this procedure.

(c) The person buying the organ must pay all recovery costs of the provider until an arm's-length doctor, not directly involved, certifies that the provider is healthy enough for regular activity and the recipient is ensured that there are no complications, such as rejection.

(d) The provider or any of his family is not beholden to the recipient or any of his family and vice versa.

(e) The recipient must have an insurance policy in place to cover the loss of income or possibly life. Due to the possibility of complications, both parties must be free of any liability, and this must be assured before any procedure is done.

These are just some preliminary suggestions to solve a very complicated problem. I'm sure that if we all sat down together and put aside our personal and political agendas, we could come up with a positive solution for people waiting for organs.

Bill 67 is not the way to go on this issue. It is coercive and not very Canadian.

The way it stands, it's not really clear. When I tried to get information on the health act combined with the Highway Traffic Act, there is no clear indication of what they plan on doing.

If there are two million people with driver's licences, is the state, down the road, going to say, "We have to have you confirm that your organs are good enough for us to donate"? Because there is no sense in ripping the organs out of somebody who is not healthy enough to donate their organs and to pass their diseases on to the person they thought they were doing something good for.

There has to be an alternate solution; we're just not looking at it.

The Chair: You're four seconds over your time, so you're bang on. Thank you.

PATTI GILCHRIST

The Chair: Patti Gilchrist. Welcome, Ms. Gilchrist and Mr. Gilchrist.

Mr. Steve Gilchrist: Mr. Chair, Madam Clerk, former colleagues or new members, I'm here just as moral support for the bravest young lady I've ever met.

The Chair: Brave young lady, you have 10 minutes to show us how brave you are.

Ms. Patti Gilchrist: Thank you for this opportunity to speak in support of Bill 67 and to offer a first-hand perspective on the importance of organ donation and to link that support with the outstanding competence and professionalism of those marvellous people, our doctors and nurses.

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We are all familiar with the Hollywood expression "dead man walking." Well, thanks to the generosity of a thoughtful donor and family, I appear here before you today, living woman walking, talking and enjoying life, and doing so in a way that would have been impossible without a crucial and life-saving heart transplant.

Twenty-one years ago I was diagnosed with a virus called myocarditis, an ailment that proves fatal in 95% of the people who contract it. To make you aware of the terrible incapacity, the emotions a person goes through—the anguish, the fear, the hope, the despair—and to inspire your undoubted compassion to support this worthy legislation, I will give you a brief, personal story.

In 1986, I found myself feeling ill, dizzy, suffering from blackouts and shortness of breath. I was taken to hospital and had to stay for a month on medication to stop the inflammation from around my heart. I was forced to rest at home for six months with no driving, no working and no strenuous activity of any kind.

By 1995, my damaged and extremely enlarged heart had deteriorated into congestive heart failure. I lived with that for five years. I was in and out of hospital, getting intravenous Lasix drips to reduce the inflammation around my heart.

In December 2000, I had a stroke. I was in a grocery store with my two kids, who thought I was just joking around until I dropped to the floor. At that point, I was partially paralyzed on my right side and couldn't talk. I was rushed to Cobourg hospital, and afterwards had barely started to recover and get some movement back when it happened again.

This time I was rushed to Toronto Western Hospital, where a caring and attentive group of doctors and nurses were waiting to perform a series of tests on me. It was at that time the doctors decided to put me on the heart transplant list. From there it was a question of downhill survival, requiring me to wait to undergo a heart transplant, if a heart became available. Seven long months later, on December 30, 2001, a phone call came at 3 o'clock in the morning and a voice said, "We have a heart for you."

With only three hours to get to surgery, I was rushed to Toronto General, where I received my new heart. Unfortunately, rejection was immediate. My heart had to go through three blood washings, and I began a critical 48-hour intensively monitored waiting period. The doctors had told my family that if I survived this period, I would possibly be okay. As it turned out, I was forced to stay in the cardiovascular intensive care unit and was intubated for two weeks. When I finally got to a regular hospital floor to start recovery, I found that I was partially paralyzed because my muscles had atrophied.

I was in Toronto General for over a month and then sent to St John's Rehabilitation Hospital, where I spent three more weeks learning to walk and use my upper body again. It was the toughest thing I have ever done.

What a miraculous turnaround to a person's life, all brought about by the most extraordinary gift a person could ever receive. Words fail. Compassionate? Generous? Unselfish? Magnanimous? How could I ever hope to describe my feelings of gratitude to my unknown, kind and caring benefactor?

Because of the generosity of this donor, of his or her family, I now get to watch my kids grow up and to spend time with my loving family and devoted friends. Experiences like mine make us realize just how much we love and depend on the people who are our biggest supporters: in my case, my mom and dad, Pat and Gord; my daughter Dallas; my son Dakota; my sister Peggy; my nephews Craig and Stevie; and my wonderful brother and your friend, Steven Gilchrist.

I also get to enjoy my neighbours and best friends, Margaret and Steve Tallon, and their kids, all of whom I love very much and who went far beyond simple friendship to be of immense help both before and after my transplant.

Every day, my overly concerned parents would drive over 100 kilometres to Toronto General to sit with me. The aftermath of my operation was a combination of medication-induced sleep or, during my waking hours, considerable pain and almost no ability to communicate. Still, there they sat, hour after hour, talking to me to keep me company. The first couple of nights, in order to stay as close as possible to the hospital, they slept on my brother's office floor and couch here at Queen's Park. I can't thank them enough for the love and support they showed to me and my children during those anxious days.

My brother Steve would visit me every afternoon or evening as well. He too would sit there with me even if I couldn't talk to him. My sister took my two worried kids into her home and made sure that they were well looked after and got to school every day.

My best friend, Margaret, also pitched in wonderfully. She took great care of both me and my kids before and after the transplant. She made sure I had groceries, that my house was clean, that my laundry was done, and ran hundreds of errands. Margaret and her husband, Steve, made my house into a virtual bungalow—everything on one floor—because I couldn't climb stairs. Margaret would stay with me until I went to sleep at night, just to keep me company. I am truly blessed to have such a wonderful family and such wonderful friends.

This past December, I turned five. I am now looking forward to the next five years. In 2011, I will receive a 10-year pin.

During the first year after my transplant, I had to undertake weekly biopsies, then every two weeks, then every month, finally every three months and every six months, and I showed rejection. I have gone in and out of mild rejection several times in the last five years, all

controlled and regulated by many different pills. It has been nine months since the last rejection, and if I don't have any rejection in my next six-month biopsy, I may never have to have another one again. How amazing.

The punchline to this story is that now, five years later, after an almost hopeless future, I have been rejection-free for nine months. I am healthier now than I was 21 years ago, and although I tire easily if I do too much, I'm able to lead an active and fulfilling life. All of this is because of one donor who had the compassion, the generosity and the humanity to offer the gift of life with his or her heart to a stranger.

I believe that's what Bill 67 is all about. It is here to help many people, your friends and my friends and neighbours, to continue their useful lives with their loved ones. I am grateful beyond words for my gift, and I will always be mindful of the pain the donor's family must have suffered that fateful night five years ago.

What does trouble me is that many of the people I met while I was on the waiting list for a replacement heart did not live long enough to experience the same life-saving operation I received. My doctors tell me that only a small fraction of those who need a heart or kidneys or lungs or other organs get them, and that hundreds of Ontarians die needlessly every year because there are simply not enough organ donors.

So I want to extend a grateful thanks to Mr. Klees for bringing forward the same kind of legislation my brother introduced five years ago in this House, after he had seen, first-hand and personally, the wonderful benefits that organ donation can have. Steven told me that his biggest disappointment in his eight years at Queen's Park was that his Bill 17 did not receive the necessary and compassionate, life-saving, unanimous consent. While five years and many lives may have been lost, it is clearly a case of better now than never.

I believe it is entirely reasonable to ask people to answer "yes" or "no" as to whether they wish to be organ donors when they complete an application for a driver's licence or health card. And it is just as important that the organ donor's personal wishes be respected. No other family member should have the right to overturn the decision and generous wishes of a would-be donor. By making these simple rules, I believe there will be a dramatic increase in the number of donors, a shorter waiting period for donations, a shortening of the anguish of waiting, and more Ontarians able to quickly return to productive and healthy lives.

Ladies and gentlemen, thank you once again for this opportunity to share my story with you and to speak out very strongly in support of Bill 67. May your compassion govern your actions and inspire your support of this worthy legislation.

The Chair: Your brother described you well.

We have about two minutes, Mr. Klees. I'm going to give the two minutes to you.

Mr. Klees: Patti, I want to thank you for sharing that story and for putting real meaning to what otherwise is just another piece of legislation. I remember Steve

battling through this with you. I also remember him bringing forward his bill, and I remember the very sad day in this Legislature when unfortunately, for nothing other than political reasons, we didn't get that unanimous consent. In the same way that Steve no doubt feels that probably in his eight years here that was the greatest disappointment, I would feel that, if this government saw fit to set aside everything except the principle of doing the right thing, to see this bill pass would probably be the best thing that has happened in my 12 years here.

I think everyone recognizes that this is not a silver bullet. This is not the end-all and be-all. We're not suggesting that this is the answer. We've heard from even you today that what we really need is to ensure that the wishes of an individual are totally respected, that they can't be overturned. I agree with you, and I think that's an important next step that we have to take as a government as well.

I wish you well. I thank you for being here. When this bill passes, I want to dedicate it to you.

Ms. Gilchrist: Thank you very much. Thank you for the opportunity.

Mr. Klees: Steve, thank you for being here.

Mr. Gilchrist: Thank you all.

Not in any way to attempt to embellish what my sister has so ably said, but this really is a non-partisan issue. I don't know how you could read politics into this. I wish it had not been that my family had gone through an experience that allowed me to have that perspective, but it did, and I hope you never have to go through that. But the responsibility we all share, government and opposition, is always to do what's in the greatest good. I really can't see any reason why this piece of legislation would not be seen as a reasonable and modest step forward towards that goal of a more complete organ donation system.

With that, thank you, Mr. Chair.

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The Chair: Patti, the last 20 seconds to you. You have 20 seconds if you want to offer anything else.

Ms. Gilchrist: I just think it's a very important and worthy cause. I wouldn't be here today if it wasn't for the donor I received a heart from. I watched a friend of mine who received a double lung transplant who also wouldn't be here if it wasn't for that. It just makes for a new life. I can now watch my kids grow up and spend time with them, which I wouldn't have had a chance to do.

The Chair: Thanks for sharing your story.

THE CANADIAN FEDERATION OF UNIVERSITY WOMEN/ONTARIO COUNCIL

The Chair: The Canadian Federation of University Women Ontario Council. Welcome, Elaine. Please state your name for the record and then share your views with us.

Ms. M. Elaine Harvey: My name is M. Elaine Harvey. I'm the chair of the legislation standing com-

mittee of the Canadian Federation of University Women Ontario Council.

Mr. Chairperson, members of the standing committee on the Legislative Assembly, presenters and guests, it's an honour to stand before you. I thank you for providing the opportunity for me to make an oral presentation before this committee.

I understand from the April 10, 2007, news release of Mr. Frank Klees, MPP for Oak Ridges, that Bill 67 has received all-party agreement for these public hearings. This is democracy at its best, with the parties in agreement that public hearings be held and with the opportunity for constituents to provide input not only at this committee meeting but also in the public fora that have already been held in numerous locations around the province. I had the privilege of attending the one held in Kingston.

Now, I do apologize. I do have one copy of what I'm reading here but I don't have copies for the members. What you have received, though, is a copy of the letter that Mr. Klees referred to in his introduction that was sent to the Premier and to other people, including Mr. Klees.

I'd like to point out, though, that in Mr. Klees's enthusiasm for this bill and its potential for saving lives, we must excuse him for misreading the letter from my organization. If you look at the beginning of paragraph 3, it says that, "what the application allows for"—according to Hansard, from Mr. Klees—"is a yes, a no or an undecided," but "the option to say 'no' is not included in the bill." It's not the option to say "undecided" but the option to say "no." Certainly, that can be excused, but it's important to recognize that, particularly in view of the clause-by-clause discussion next week.

CFUW Ontario Council is not opposed to increasing organ donations. In fact, our national organization has a policy entitled Organ and Tissue Donation Awareness in Canada, adopted in 2002.

I might just say that I live in Kingston, and when I picked up the Kingston Whig-Standard this morning there was a headline on an inside page saying, "Organ Donation Refused." I wondered what that was all about, and then I saw a picture of a large theatre organ that they wanted to find a home for and they hadn't found a home for it.

What our organization is vitally concerned about with the proposed Bill 67, Organ and Tissue Donation Mandatory Declaration Act, are three things:

(1) the limitation of choices in the proposed declaration;

(2) the limitations in soliciting public opinion and the subsequent conclusions that may arise;

(3) the potential for seriously increasing the cost of health care in Ontario.

First, I will consider the limitation of choices in the proposed declaration. As you know, the bill at this stage requires any person applying for or renewing a driver's licence or health card to make a declaration on donating their own organs and tissue when they die. But only two

choices are offered: Yes, they are willing, or they haven't decided yet. The declaration does not provide for the option to say no. One must choose either to agree that one's organs be donated or declare that he or she has not yet made a decision. Without making such a declaration, the individual will be denied the driver's licence or health card that is being applied for. To deny a citizen either of these cards can and likely will involve severe hardship for that person. Is not this too severe a penalty for refusing to donate one's organs on death?

For the "no" option to be denied, I assert, is an infringement on the human rights of the individual to declare his own wishes regarding this aspect of his death if he or she wants a driver's licence or health card.

There is one other option for that individual, but it is equally unpalatable. That person could make a false declaration by affirming that they haven't decided yet. This is the only other option available under the present bill. So this legislation will be either an infringement on human rights for those who believe in keeping the body whole after death or it will be an invitation to the individual to declare an untruth on a legal document by declaring that he or she has not decided yet when, in fact, the decision has already been made to deny the removal of body parts. In other words, this legislation would either deny the human rights of that individual or encourage him to break the law by declaring an untruth on a legal document.

Even though those attending the public forum on this bill in Kingston were told otherwise, some people would oppose making organ or tissue donations for themselves due to religious or faith reasons. We were told that there are no religions that oppose organ donations. In fact, Bill 33, the Education Amendment Act (Organ Donation Education), exempts students from education on the importance of organ donations on the basis of religious belief, cultural beliefs or prohibitions and similar reasons. In addition, I have had assurances from both Buddhists and Muslims that many who adhere to these faiths would not want their body parts or tissue donated at the time of death. There are those who believe that the extracting of organs from an individual interferes with the departing of the spirit from the body, and they believe this is a significant part of the living and dying process.

With the cultural diversity of present-day Ontario, the government should be very sensitive to the cultural beliefs and practices of those of diverse ethnic and religious origins so that their rights are respected. Some would be concerned with the quality of the afterlife of one whose organs had been removed at death. Some would not agree with the medical definition of death that is used when organs are cut out. So this bill, as it stands, would contravene religious and personal freedoms.

Recommendation: I propose, then, that a third option be included in the bill that would allow individuals to select "no" as an option when asked if they wish to donate their organs upon death. The bill at present, as provided on the website of the Legislative Assembly, does not provide this option.

I will now consider the limitations in soliciting public opinion and the subsequent conclusions that may arise. I commend you for soliciting public opinion in the form of an online questionnaire and providing public fora at which hard copies of the questionnaire were provided. However, I have concerns about the questionnaire because it completely discounts individuals who hold beliefs that oppose the harvesting of human parts at the time of death and provides a limited choice of answers.

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For those who, as an act of faith, believe in keeping the dying and dead body whole, how do they answer question 3 of the questionnaire, which is: Have you advised your next of kin or designated executor about your wish to donate organs upon your death? These people do not agree with the assumption implicit in the question that the responder agrees to donate his or her organs.

How do they answer question 5: Do you have concerns about barriers to personal organ donation? Those people may be concerned that there are not enough barriers, just the opposite of what the questionnaire expected.

Question 12: Is there anything else you would like to say about increasing organ donations? How can individuals speak about increasing organ donations when they are totally opposed to them? I believe this question is meant to solicit any response not provided by the questionnaire, but it limits the answers to those who support organ donations for themselves.

The online questionnaire would not allow a person to continue to a succeeding page of questions without answering all the questions on the present page. So to read the whole questionnaire, one had to answer questions for which they had no answer, due primarily to the preconceived assumptions of those questions, but also to the limited choice of answers.

When I went through and did the questionnaire myself, I actually faked some of my answers because there was no proper answer that I could give and I did want to read all of the questionnaire.

The questionnaire is seriously flawed because the questions assume that the respondent agrees with organ transplants. Responders who oppose donating their own body parts would, without intention, skew the results of the survey to the extent that the validity of those results must be suspect. Others who oppose would not complete the questionnaire. Any conclusions reached from the data collected would be skewed because of the exclusion of those who do not agree with donating body parts.

In addition—

The Chair: Can you wrap up, please? You're about two minutes over already.

Ms. Harvey: I'm sorry?

The Chair: Can you wrap up? You're two minutes over already.

Ms. Harvey: Oh, dear. All right.

The other thing I want to point out is that the potential for seriously increasing the cost of health care in Ontario is there. There is the ever-ballooning cost of our health system for which we seem to find no bounds. The cost of

the operations, of all the medical procedures that are involved in harvesting organs and in transplanting them, is something that I would like to know, whether there has been any costing done.

The Chair: Thank you.

Ms. Harvey: I urge you to include the “no” option in the declaration, and to keep in mind that the data collected was skewed in such a way that the voices of those not wanting their own body parts donated were severely silenced.

I would like to see some costing of the procedures that would be involved with the addition of these organs. I know there is some saving in this, but I think there could be a much higher expense there.

Thank you very much.

The Chair: We appreciate those good points. Thank you.

Mr. Klees: Chair, with your indulgence, I just want to clarify that in fact it is the “no” option that will be included in the amendment, as you’ve requested.

Ms. Harvey: Thank you.

The Chair: You had stated that earlier and you’ve restated it. Thank you very much.

Thank you, presenter.

CAMPAIGN LIFE COALITION

The Chair: Campaign Life Coalition. Needless to say, we will extend your time a little beyond so that you get your full 10 minutes as well. I’ve been a little lax as Chair. When you have a minute left, I’ll just tap the hammer.

Mr. Dan Di Rocco: Thank you. I’m looking for Dr. Shea to join me here at the desk. My name is Dan Di Rocco.

Campaign Life Coalition is in favour of organ donation which does not end the life of the donor. The need for kidney and liver transplants, for example, is great and individuals can donate these organs without jeopardizing their lives. We recognize this truly as an act of sacrifice and kindness. However, we consider the present proposal, Bill 67, as unacceptable for a number of reasons.

This proposed legislation compels all people to make a decision about an important matter. Coupling the declaration with a driver’s licence renewal, for example, is bad timing. It takes a totally bureaucratic piece of paper called a driver’s licence and attaches to it a whole set of values. People should be able to think seriously about what they want done or not done with their organs. It is not the prerogative of the government to coerce the decision in any way or to force people into making any decision on the issue.

Some of our concerns have to do with definitions, phraseology and technical wording. I’ll only address a couple of these. The wording seems to presume only the use, not the non-use, of the organ or tissue. Where is the simple response of “No, you may not use my organs or tissue”? And you’ve already answered that, Mr. Klees. Thank you.

The opt-out category of “undecided” does not take into account other possible objections such that other options should be recommended for consideration, such as “I object” or “I fundamentally disagree with the provision of my human tissue being transplanted or subject to another use or used for research after my death.”

What is meant by “uses”? Who decides on the “uses”? Is the declaration to be inclusive or exclusive? Does it specifically permit the individual to refuse any and all use of their organs or tissue? We’re not legal experts, but the wording of subsection 11(5) is troubling. People would become organ or tissue donors automatically, by default, because they failed to indicate otherwise. A person’s consent to some action should never be presumed. Any action would be valid only if such consent were expressly stated and freely given.

The question about the person being undecided has already been dealt with by other people, but we find that troubling as well.

A couple of other questions: Would the quality or availability of health care be dependent on whether the patient had or had not made a declaration donating his organs or tissue? Would the quality of care that an individual receives before death alter in any way once a person has committed to donating his or her organs or tissue?

In conclusion, all residents of Ontario currently enjoy the freedom to donate their organs or tissue by so indicating in writing. Whether it is recorded on a driver’s licence, health card or the existing donor card of the Trillium Gift of Life Network, the central registration program should be enhanced, but only on a voluntary basis. What has been considered a generous, conscious act of charity and selflessness in the past would be transformed into a coerced duty, a new social expectation. Most jurisdictions have adopted the strictly voluntary approach. The onus should remain on the individual to take the step of declaring himself or herself as a donor of their organs or tissues.

The proposed amendment is discriminatory and statist by coupling a civil privilege and a basic right to something that is otherwise unrelated. We have set up health coverage and driving privileges for citizens as part of the movement toward social welfare and utility. The suggestion that a citizen will be required to state on a licence renewal form or health card application what he or she will do with one’s organs is a rather drastic intrusion into one’s personal autonomy. The government would be placing unfair and odious conditions on a customary privilege or right to health care, perhaps endangering the security of the person guaranteed by the Charter of Rights and Freedoms.

In summary, this type of legislation is not necessary. It is dangerous and open to abuse. Its practical goals could be achieved through less intrusive, less dictatorial and more cost-effective means. The legislation constitutes an unwarranted intrusion by government into the private affairs of people. There are also medical and ethical concerns that would be exacerbated by commercial pressures to gain access to organs and human tissue.

1730

Dr. John Shea: Human organs are retrieved after a person is declared by a physician to be brain-dead or to have suffered cardiopulmonary death, also known as cardiac death. In truth, neither brain death nor cardiac death are equivalent to actual death.

First, brain death: In 1968, the Harvard ad hoc committee on irreversible coma stated that brain death, the irreversible loss of brain function, should be regarded as death because a patient in an irreversible coma is—and these are their words—for all practical purposes, if not in reality, dead. This oxymoron has caused confusion ever since. The truth is that although most persons who are declared brain-dead will die within 48 hours, some survive to lead a normal life. Some brain-dead pregnant women have survived for up to four months and delivered a normal child. I personally know a physician who has survived brain death.

Cardiac death: This concept was introduced in Pittsburgh in 1993. The Institute of Medicine describes a typical case: A person five to 55 years old, otherwise in perfect health, suffers a brain injury, either in an accident or from a stroke. Typically, this person is put on a ventilator to assist breathing, is in a coma and is sent either to an emergency department or an intensive care unit in a hospital. There, a physician decides as soon as possible, so that the organs may not be damaged by lack of oxygen, and completely arbitrarily that the treatment is futile and the patient's condition is hopeless. The relatives are told this and are asked to consent to withdrawal of ventilatory support. Only after obtaining that consent are they asked to agree to organ donation. The physicians wait until the heart stops beating. Five minutes later, they retrieve the organs. Some wait only two minutes. Some, like a hospital in Denver, wait 75 seconds. After the decision is made to allow organ retrieval, which may be long before the heart stops beating, some physicians inject the patient with blood thinners and dilators to help preserve the organs, even though this would seriously harm any other patient. If the heart does not stop beating within an hour, the organs are regarded as being too damaged by lack of oxygen and the patient is allowed to die without any effort at resuscitation.

A patient who has suffered brain injury may die, may recover completely or may recover with a varying degree of brain damage. No one can, especially in the early stages, truly know what the outcome for the patient will be. The most egregious aspect of cardiac-death organ retrieval is that the withdrawal of ventilation is the prime cause of the patient's death. This death is not due directly to disease or accident, but due to the deliberate act of a physician who knows in advance that he or she may cause that death.

I have appendix A and appendix B, which are two articles I have written with 26 scientific references, in which you can check this out.

Mr. Di Rocco: We recognize and appreciate the need for increasing organ and tissue donation, but this legislation is not necessary. This particular legislation is flawed. It represents a massive intrusion by government

into private matters, it is coercive in nature, it mixes apples and oranges, it appears to support a strictly utilitarian view of the human person, and there are medical and ethical concerns. There are better ways of achieving the goal of increased organ and tissue donation rates.

The Chair: Thank you so much.

SUSAN SMITH

The Chair: Susan Smith is our final presenter.

Ms. Susan Smith: Good afternoon. I want to thank the committee very much for this opportunity. I apologize for being here without my prepared copy. Actually, what I have, which I would like to leave with the clerk as an appendix, is a copy of a piece of research, a protocol being done in London, Ontario, where I come from, with respect to donation of a particular bodily fluid, just for reference as background for the committee, for you to have that. So without my notes, my comments will be very brief.

The largest flaw I see with this bill—I hope this will be taken as a constructive suggestion, Mr. Klees. I think the application for a driver's permit, actually the first application for a graduated driver's permit, is absolutely the most appropriate document to be used to solicit thoughtfulness in consideration of the issue and a deliberate response from Ontarians. I don't see the health card the same way, and I'll try to put it in context. But I certainly feel that the application for a driver's permit is the correct document to use. I would just parenthetically add that I would hope that hard-copy application would always be available for either re-applying for a driver's permit, for renewing it, or for an initial application and that it not only be done electronically online.

My perspective on why the driver's licence—and I'm certainly suggesting, as you go forward with this, that it be a staged thing and that it be implemented for driver's permits first without trying it on the health cards. I think the fine for not doing up your seatbelt still is something in the area of just \$1,000; it might even be less than that. The kinds of fines that we have for impaired driving charges, upon conviction—to put that in context on the totally preventable side, we're not doing enough with the sticks, if you will, instead of the carrots, for eliciting responsible behaviour around motor vehicle use, which is exactly why I see this bill in the appropriate context with driver's permits for both renewal and for initial application for a permit. Because it is a permit. I don't see it as a licence. That might be the terminology used, but it's actually a permit based on proof of eligibility and ongoing behaviours that indicate a renewal is in order.

One aspect, though, of the driver's licence—I've heard Minister Cansfield refer to what's coming down the line for a new driver's permit format, for—I don't know if it bears any relation to what the American permit will look like—ease of border crossing and that kind of thing. So if there are areas or issues of security, of protection either of Ontarians' information, identity or any other kind of bodily integrity, I would hope that that would be looked at very carefully.

From the comments that I've heard from other presenters, certainly people have fixed on what isn't in this iteration of the bill, wanting the "no" option. My only comment that I will make about that, I suppose, is somewhat anecdotal. I come from London, Ontario. To the best of my knowledge, Dr. Bill Wall, who is a transplant surgeon at University Hospital, is doing a transplant today. In recent months, within the last 12 months, congestive heart failure has been reconsidered medically, within the protocols, as now being a factor in which an organ can be taken. There have been some studies that looked at whether someone's congestive heart failure admission to a hospital on a weekend as opposed to a weekday was an issue in either certain types of treatment in situ or actual survival for a short period of time.

1740

Beyond that, my question—because you get to ask me questions—very seriously is: To what extent has this bill been thoroughly cross-referenced by your researchers with Bill 171? That's a really large document. It has got a lot of detail in it. It's an omnibus bill, so I would ask you to really think about that carefully, as you look at the shorter number of pages of this bill and the proposals that come forward, but just making sure that you're looking at Bill 171 in its entirety and reflecting through every piece of how you are staging this legislation.

Those are my comments. Thanks.

The Chair: Thank you very much. We have four minutes: two minutes for the government side and two minutes for the opposition side. Does anybody on the government side have a question?

Mr. Kular: Am I answering her question?

The Chair: No, you don't have to answer her question; it was a research question. But do you have a question? You can answer her question if you want, but I think it was more referenced to research. Do you have a question?

Mr. Kular: No.

The Chair: Okay. We'll go to the opposition side.

Mr. Klees: Thank you so much for your presentation. I'll try to answer your question of whether this has been referenced to Bill 171. We're trying to figure out Bill 171. This bill, as you point out, is really very, very straightforward. It's essentially a one-pager and it is really only an administrative measure. It doesn't deal with many of the other issues that were raised here in terms of how the organs are harvested or at what point in death. We're dealing strictly with an administrative measure here that's intended to give individuals in the province of Ontario an opportunity to consider the issue of organ donation. There's no intention at all of forcing a

decision, which is why the options of "yes," "no" or "undecided" are provided, because if someone is uncertain, they simply need to tick off the "undecided" box on the question.

I am appreciative of a number of the issues that were raised today. It's something that obviously we have to consider further. I think we tend to make the very simple proposal here that is contained in this bill perhaps something more complex. The government will have to deal with all of those other issues, and it will. We've got 26 recommendations that came forward out of the citizens' panel that was commissioned by the Minister of Health. A lot of those recommendations deal with many of these other circumstances.

This bill does not go into any of that discussion. It is simply asking the government to provide a facility on both of those cards, to give people an opportunity to consider it and to raise awareness. The objective is that at the end of the day, with more people who actually take the time to think of it and hopefully make the "yes" decision, the result will be more availability of organs for transplant, with the end result that lives will be saved.

We'll see what happens as the process for this bill continues, but I'm certainly hopeful that we can and will be able, as a committee, to focus on the intent of the bill and not allow a lot of these complexities that will have to be dealt with in other legislation to keep us from at least making this important step forward.

I want to thank all of the presenters today. You have raised very important issues.

The Chair: Indeed, yes. Thank you.

The last 30 seconds are to you, Ms. Smith.

Ms. Smith: I'd like to underscore as clearly as possible the degree that I see this as appropriate on the driver's permit. I see it as not appropriate on the health card.

The Chair: So noted. Thank you very much for your presentation.

Members of the committee, we will reconvene next Thursday morning to go through public hearings on Bill 164, the next piece of legislation this committee is looking at, and come back at 4 o'clock to do clause-by-clause consideration of Mr. Klees's bill, which we had public hearings on today.

For administrative purposes, the clerk points out to me that proposed amendments should be filed with the clerk of the committee—that's for Mr. Klees's bill—by 6 p.m. on Tuesday, April 24. Everyone has noted that?

The meeting's adjourned. Thank you.

The committee adjourned at 1745.

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