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Wednesday 22 April 2009

Journal des débats (Hansard)

Mercredi 22 avril 2009

Standing Committee on the Legislative Assembly

Comité permanent de l'Assemblée législative

Employment Standards Amendment Act (Organ Donor Leave), 2009

Loi de 2009 modifiant la Loi sur les normes d'emploi (congé pour don d'organe)

Chair: Bas Balkissoon
Clerk: Tonia Grannum

Président : Bas Balkissoon
Greffière : Tonia Grannum

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON THE LEGISLATIVE ASSEMBLY

COMITÉ PERMANENT DE L'ASSEMBLÉE LÉGISLATIVE

Wednesday 22 April 2009

Mercredi 22 avril 2009

The committee met at 1302 in room 151.

SUBCOMMITTEE REPORT

The Chair (Mr. Bas Balkissoon): We'll call the meeting of the Standing Committee on the Legislative Assembly to order. Report of the subcommittee on committee business: Mr. Delaney?

Mr. Bob Delaney: Your subcommittee met on Wednesday, April 8, 2009, and Monday, April 20, 2009, to consider the method of proceeding on Bill 154, An Act to amend the Employment Standards Act, 2000 in respect of organ donor leave, and recommends the following:

(1) That the clerk of the committee, with the authorization of the Chair, post information regarding public hearings on Bill 154 on the Ontario parliamentary channel and the committee's website.

(2) That the clerk of the committee also send information regarding the public hearings on Bill 154 to Canada NewsWire.

(3) That interested parties who wish to be considered to make an oral presentation on the bill contact the clerk of the committee by 3 p.m. on Monday, April 20, 2009.

(4) That the committee meet for public hearings on Wednesday, April 22, 2009, during its regularly scheduled meeting time and subject to witness demand.

(5) That the length of time for all witness presentations be 15 minutes.

(6) That the deadline for written submissions on the bill be 12 p.m. on Wednesday, April 22, 2009.

(7) That the administrative deadline for filing amendments be 3 p.m. on Monday, April 27, 2009.

(8) That if no public hearings are required, the committee meet one day for clause-by-clause consideration of the bill on Wednesday, April 22, 2009.

(9) That if public hearings are required, the committee meet one day for clause-by-clause consideration of the bill on Wednesday, April 29, 2009.

(10) That the research officer provide the committee with background information prior to public hearings on the bill and that the research officer provide the committee with a summary of witness testimony prior to clause-by-clause consideration of the bill.

(11) 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 (Mr. Bas Balkissoon): Thank you. Shall the report of the subcommittee be adopted? Agreed? Agreed.

EMPLOYMENT STANDARDS AMENDMENT ACT (ORGAN DONOR LEAVE), 2009

LOI DE 2009 MODIFIANT LA LOI SUR LES NORMES D'EMPLOI (CONGÉ POUR DON D'ORGANE)

Consideration of Bill 154, An Act to amend the Employment Standards Act, 2000 in respect of organ donor leave / Projet de loi 154, Loi modifiant la Loi de 2000 sur les normes d'emploi en ce qui concerne le congé pour don d'organe.

TRILLIUM GIFT OF LIFE NETWORK

The Chair (Mr. Bas Balkissoon): Now we will move to deputations. Our first deputant is Mr. Frank Markel, president and chief executive officer, Trillium Gift of Life Network. You have 15 minutes. Please state your name for the record, and if there's any time left at the end of your deputation, there will be questions from everyone.

Dr. Frank Markel: My name is Frank Markel. I'm president and chief executive officer of Trillium Gift of Life Network, Ontario's organ donation organization. I don't know if it's coincidence, but you are holding your hearings in the midst of National Organ and Tissue Donor Awareness Week, so in the package I've brought I include a green ribbon or a trillium button. You can make your choice, but I hope you wear one to indicate your support for organ and tissue donation.

I have a presentation that's included in the package. If you could turn to it, I'll take you through it very briefly.

The second slide on that presentation invites you inside the world of organ and tissue donation. The young man whose picture you see there is actually the hero of our new website, RecycleMe.org, which Mr. Caplan unveiled on Monday. It's a website dedicated to youth, but it has a great deal of information about organ and tissue donation and I invite you to have a look at it.

I'm here to talk specifically about Bill 154, which would provide unpaid leave for living donors, unpaid leave from their employment, so I thought I would begin by showing you some statistics about living donation.

The two major organs which can be transplanted from a living donor are the kidney, which is the most common, and then secondarily the liver. The third slide in my presentation shows you time trends going back to 2002 in terms of both kidney transplants from living donors and liver transplants. What you see is that in Ontario, in that time span, we have managed to increase substantially the number of living donors, but to my eye, in the last few years, the increases have not been maintained. We have held steady, but the pattern of increase that we saw at the beginning of the decade has not continued. I think that's one reason why this bill deserves your consideration.

Living donation shares that record with deceased donation. At the bottom, slide 4 shows you the record for deceased donation in the province and the waiting list. We have made increases in the number of deceased donors in the last three years. For many years, Ontario ran at about 150 deceased donors a year. In the last three years, we've gotten as high as 200 and, in the most recent year, 175. Our waiting list of those awaiting transplant has diminished somewhat from 2004, as you can see with the red line, but it remains at almost 1,700 people.

I won't take you through in any detail the next slide. It shows you detailed statistics on transplantation in Ontario by fiscal year. But you should realize how important living donation is to transplantation. Over 40% of kidney transplants come from living donors, and about a third of liver transplants come from living donors. In particular, you'll hear later this afternoon from Dr. Levy from the University Health Network. They have one of the most highly regarded living liver donor programs in the world, and people come from all over the world to learn from them. But we still need more donors, as the slide I showed you shows.

I've shown you a picture of a world in which it would be easy to get all the donors you needed. You see the advertisement for Kidney Depot. Of course, you know it's illegal to buy and sell organs in Ontario. This, again, is from our youth campaign announced on Monday. These humorous posters are now in buses across the province—38 different cities—trying to reach youth to get to this website, RecycleMe.org. But that isn't the solution, and that's why this legislation is important.

Of the almost 1,700 people waiting for transplant, you can see on slide 7 the breakdown by organ. The majority are waiting for a kidney—over 1,100 people waiting for a kidney—and then second, over 300 people waiting for a liver. These, as I said, are the two organs for which it is possible to be a living donor, so I think these statistics show you quite clearly the importance of living donation in terms of reducing the wait list.

In August 2007, Premier McGuinty announced at the Trillium offices the Premier's initiative on organ donation, following a report from the citizens' panel. That Premier's initiative has a number of elements to it, just one of which is Bill 154, which would provide unpaid leave for living donors.

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In my next two slides, I want to talk to you about why this bill is important. As I've suggested to you, our earlier record of strong increases in living donation hasn't been matched in the last three years provincially, so we do need help in increasing living donation.

I'll make the point in a moment that this particular initiative, Bill 154, fits very nicely with other elements of the Premier's initiative, particularly the program for reimbursement of expenses for living organ donors. That program, which we call PRELOD, reimburses living donors for a number of expenses, including lost income. When you think about that for a moment and you see the linkage between Bill 154, which guarantees leave of absence, along with the PRELOD program, which provides income supplement, I think those two work very nicely together.

Let me give you two other reasons why I think this bill is so important. Today, absent the bill, an individual who has decided to be a living donor essentially has to ask a favour of his or her employer, has to ask for leave. I don't think anyone should have to go to their employer to ask for leave if they're being generous enough to donate an organ. After all, you wouldn't expect women to ask for leave to have a baby.

This is my view, and I'm not a politician, but I also think it's very important to the public of Ontario to see that there is a consensus of support for organ and tissue donation as expressed by government in a variety of ways. I think this is yet another way in which the government can make clear its support for organ and tissue donation.

Now let me speak, in the next two slides, to some of the details of the PRELOD program so you can understand the loss-of-income supplement that it provides. It provides that loss-of-income support to those individuals who are actually living donors and are off work to recover from surgery. The donor must experience a financial loss because of their absence. The time off work to attend assessment visits is not part of the reimbursement, and this program is not applicable to out-of-country donors; it's applicable only for donors from within Canada for a recipient in Ontario.

The second slide shows you the amounts. We pay up to $3,200, $400 a week or 55% of the individual's net earnings, whichever is less. We pay that, depending on the advice of the surgeon, for either eight weeks or sometimes up to 14 weeks. First of all, the individual must exhaust other sources of income, and they're listed here. It's a deductive process that results in our arriving at the sum. My main point is that while the bill provides for unpaid leave, it is complemented by the PRELOD program, which does provide income supplement.

Finally, I'll mention to you some of the other aspects of the Premier's initiative, all designed to build support for organ donation. We are working very closely with religious leaders in the province to ask them to show

their support, and you can see some of the groups we're working with: the Toronto Board of Rabbis, the Catholic Archdiocese of Toronto, the council of grand chiefs and the Ontario Council of Imams. For all of these groups, we either have or will have shortly brochures written by the religious leaders or the faith leaders themselves in their own language, indicating their faith's support for organ and tissue donation. The one in your package is from Grand Chief Stan Beardy of the Nishnawbe-Aski Nation. We've given you the one in English, but we have it in Cree and Ojibwa as well to make it accessible.

Finally, again as part of the Premier's initiative, we're trying to reach the youth of our province. One tactic we're using is to provide an educational program in the grade 11 curriculum. It's called "One Life ... Many Gifts." There's a website related to it. We're now teaching it in 20 school districts across the province, and on Monday, Minister Caplan announced continued funding, so we can get to every school district.

I'll close, then, by reminding you, on the very last page of this new website, RecycleMe.org, for young people—we do maintain our ongoing website for the general public, giftoflife.on.ca, and invite you to visit either of those.

That concludes my presentation, Mr. Chair. I'm happy to answer any questions.

The Chair (Mr. Bas Balkissoon): Thank you very much. We have about one minute each. Mr. Miller.

Mr. Norm Miller: Thank you for coming in today. I just have a minute, so I'll be quick. This will make, hopefully, a small difference in encouraging more people to donate organs. Certainly that's my goal and I'm sure your goal.

Frank Klees had a private member's bill initiative a couple of years ago that would have required people to choose when they're applying for a health card or driver's licence—I think it would be "yes," "no," or "don't know." You'd have to make a choice, anyway, so that everybody would have to make a conscious decision about organ donation. Do you support an initiative like that?

Dr. Frank Markel: I support an initiative that has something in common with it but differs in an important way, and actually the government, in December, initiated it exactly the way I would like to see it done, which is to register only people who want to be donors. We now have what we call an affirmative registry in Ontario. If you're not interested in being a donor, that's your own business; you tell your family, and we respect that. But it goes back to my wish that the government show its support for the cause of donation. I think the government should be in the business of recording the names of people who want to be donors. I like the idea of registration, but I think it should be an affirmative registry only.

Mr. Norm Miller: I agree with that. It's just I'd like to see everybody consciously make that decision so that we get many more donors.

Dr. Frank Markel: Right.

The Chair (Mr. Bas Balkissoon): Thank you. We'll now move to the NDP. Mr. Kormos?

Mr. Peter Kormos: Thank you kindly, sir. You know you and I continue to disagree about affirmative versus—I say we live in a regime of presumed denial. But that's not the issue today. We're going to support the legislation. It's going to pass before the summer break; I can almost guarantee that.

In the Legislature I've talked about how Ted Arnott's Legion card, on the back of it, had an organ donor card. I'm not sure whether all Legions do that, but I was awfully impressed. If you could get more partners of those types of groups that have cards—credit card companies could do it; any number of sources.

The other thing is, of course, as you and I talked about, wouldn't it be great if Canadian Tire gave a 2% discount when you presented your organ donor card? That would be a great corporate partner.

But I'm looking at the waiting list here: 1,185 people waiting for kidneys, and livers, 306. All the others would require a dead donor. Could all of those kidneys be living-donor kidneys?

Dr. Frank Markel: In theory, if anonymous donors came forward, for example, in sufficient numbers. There's no reason why anyone needing a kidney could not receive it from a living person, if that's your question.

Mr. Peter Kormos: And you need just one kidney out of the pair and you just need a little piece of liver, huh?

Dr. Frank Markel: A little bit of liver, yes.

Mr. Peter Kormos: I'm not sure how my liver would be, but I suspect one of my kidneys might still work.

But that's interesting, because how, then, do you promote—most of the focus is on dead donors. Do you understand what I'm saying? At least the perception from the public. How do you promote—you and I have talked about this—the concept of giving a kidney as readily as people give blood?

Interjection.

Mr. Peter Kormos: Seriously, without having to worry about whether it's your cousin or your family. We know somebody somewhere—1,100 people need kidneys. I'm 57 years old. Heck, if one of my kidneys is good, I really don't have that many more miles in the total scheme of things. How do you promote that?

Dr. Frank Markel: The short answer is, it is possible to have public awareness campaigns that would encourage people to be living donors. Dr. Levy, who is speaking to you later this afternoon, is someone you should ask this question as well, because he leads the Multi-Organ Transplant Program at UHN. I think public awareness of the possibility of being a living donor has value, and that's something we could consider.

The Chair (Mr. Bas Balkissoon): Thank you very much. On the government side, Mr. Delaney.

Mr. Bob Delaney: As we appear to be running short on time, I just want to thank you very much for having taken the time to come and make your deputation to us,

and I just want to say how much we appreciate your contribution to the bill.

The Chair (Mr. Bas Balkissoon): Thank you, Dr. Markel. Thanks for taking the time to present to us.

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TORONTO GENERAL HOSPITAL MULTI-ORGAN TRANSPLANT PROGRAM

The Chair (Mr. Bas Balkissoon): The next person presenting is Gary Levy, director of the Toronto General Hospital Multi-Organ Transplant Program. You have 15 minutes. Please state your name for the record, and if there's any time left there will be questions.

Dr. Gary Levy: My name is Dr. Gary Levy and I'm the director of the transplant program at the University Health Network. I'm also the director of the newly formed Toronto transplant institute, which encompasses all of the transplant programs here in the greater Toronto area. I'll get to that in a second.

First, I want to thank the committee for the opportunity of presenting to you today. I've given you a handout of what I'm going to say and I've also given you a handout of one of the questions, maybe in response: How does one solve the problem of organ donation? We have a symposium which will be going on on Monday, May 4, and the former Secretary of Health of the United States, Tommy Thompson, will be here as our guest. We're more than happy for any of you to meet with Mr. Thompson, who has played a leading role in quadrupling organ donation in the United States and perhaps he can answer the question better than I can.

As I said, I'm the director of Canada's largest transplant program and the newly formed Toronto transplant institute, and our combined programs here in the greater Toronto area perform about 650 to 700 solid organ transplants in both adults and children. Of course, the children's program has made the headlines in the last two weeks, which we're all aware of.

At the UHN, we are the largest of the contributors, with over 400 solid organ transplants, and the breakdown, as Mr. Kormos alluded to, is 140 kidneys, 130 livers, 90 lungs, 25 hearts, 25 pancreases and five intestines. Clearly we're not going to be doing living-related heart transplants—not in my lifetime. At the Hospital for Sick Children we perform approximately 60 solid organ transplants—25 hearts, 25 livers etc.—and at St. Michael's it's a renal transplant initiative.

So transplantation works. It's the most successful treatment for patients who have end-stage organ failure. I'm happy to tell you the one-year survival rates across the board are 95%; five-year, 85%, and there are no alternatives for these people. Although surveys have suggested that most Ontarians are overwhelmingly in favour of organ donation, Ontario's deceased organ donation rates remain among the lowest in North America and Toronto has the distinction of being the lowest in Canada. The only path where we've made inroads, as Mr. Markel has stated, is through living related liver transplantation, and although, clearly, living related transplantation will help us, it won't solve all of the problems. But we're here to support an important bill today.

The low deceased-donor rates in Ontario have had devastating consequences, and I can speak to that because I just came from a clinic. Wait times for transplantation are up to nine years for a kidney and two to three years for a liver, and we don't even list them for a heart because we would cause pandemonium in the community and you might be unsafe here at Queen's Park.

Every day at least one Ontarian dies waiting for a life-saving transplant, and 25% of listed liver and lung transplant recipients die before an organ becomes available. We all know this is a gross underestimate of the real impact of poor donation because we have to restrict access to these programs due to the shortage of organs. Now to help compensate for this dire shortage of deceased organ donors, we and our partner institutions throughout Ontario have established very vibrant kidney, liver and even lung transplant programs. So we actually do living related lung transplants. Today, these procedures account for about 25% to 30% of all transplants performed. They are different than deceased donation. Post-operatively, we must assume the care of the donor, who can expect to stay in hospital for about one week and then requires a period of time to recover from the surgery.

In the case of liver transplantation, which I oversee, within 12 weeks the re-sectioned liver will regenerate and grow back to full size, whereas when you give a kidney you are left with only one kidney. You do not get regeneration of that organ. But without these living-donor programs, many more Ontarians would die. As a matter of fact, when we started the liver program here in Ontario, which is world-famous for its progress, we had 100 deaths of potential liver recipients each year. That has now fallen to 50, but obviously we haven't accomplished what we set out to do.

Potential living donors undergo a rigorous and thorough evaluation which can take up to four weeks of their time, at their expense, to ensure that it is safe to perform donor surgery. Our results have shown that living donors return to normal life function, and our surveys have suggested a strong satisfaction with the donation experience. Yet despite these precautions, living donation carries significant risk of illness, and worldwide there have been at least 50 deaths of donors. We have to keep that in mind when we go forward with this. Thus, our live donor program takes the responsibility of donor care seriously, and we, on behalf of you, take all steps to protect these heroes.

Donors come from all walks of life, ethnicities and gender. Today, I saw people from all different walks who wanted to step forward to help friends, relatives and even anonymous donation, which I'm happy to talk to you about.

I'm here today to strongly support Bill 154, which will provide up to 26 weeks of unpaid leave. Any effort to encourage Ontarians to give the gift of life must be supported.

On behalf of the transplant community throughout Ontario, we applaud all elements of the government and thank you for taking this bold step. I'm happy to answer any questions.

The Chair (Mr. Bas Balkissoon): Thank you very much. We have about two minutes each, and I'll go to the NDP and Mr. Kormos first.

Mr. Peter Kormos: Thank you, Doctor. My assumption is, if I'm a liver donor, I'm going to be back to full form after that 12-week recovery period. It's going to have no ongoing negative impact.

Dr. Gary Levy: We're happy to tell you we can guarantee that because we've now published widely our experience; we have the largest experience worldwide. We've done over 500 living liver donation experiences, and 96% of patients are back at full-time employment. The other 4% chose not to go back. I consider full-time employment, incidentally, as taking care of children and other such things.

Mr. Peter Kormos: But if I give a kidney, how is that going to affect my lifestyle, if you will?

Dr. Gary Levy: The good news is, in general, they return to normal life. Our policy within the province, and we've cleared this within the Ministry of Health, is that we follow all live donors for a period of 10 years to ensure that there is no harm done to these individuals.

Mr. Peter Kormos: What's the downside, besides one kidney?

Dr. Gary Levy: There have been cases—not in Canada—where individuals have gone into renal failure and have required renal transplantation following a donation. We take all steps to ensure that doesn't happen. There have been deaths of donors. In Ontario, there was a death of a living donor. So there are risks to proceeding with living donation.

Mr. Peter Kormos: But the usual surgical risks?

Dr. Gary Levy: Yes. They're largely related to surgery and the complications thereafter; that's correct.

Mr. Peter Kormos: Is the movement one that's designed to generate kidney donation or liver donation as benign an activity as giving blood? I use that example, and I don't know whether it's fair or not.

Dr. Gary Levy: The experience isn't comparable. I don't want anyone to think that giving a kidney or a liver—and incidentally, if you want to know how much of your liver you're giving: In an adult, you're giving one half to two thirds of your liver; in a child, it's just a minor piece of the left lobe. But it's a serious operation we shouldn't take lightly. It's not the same as giving a bag of blood.

Mr. Peter Kormos: Will there ever be a shift in public opinion such that, when I know that there's somebody that needs a piece of my liver, I will simply come forward? The usual circumstance now is family or people who are intimates in one way or another, as I understand it as a layperson.

Dr. Gary Levy: Right now, at the Toronto General Hospital, we have about 80 people in workup for live donor liver transplant. Of that, approximately 15 are anonymous. They're people who called the program and are willing to step forward to help anyone in Ontario, and were, in working with the Trillium Gift of Life Network, ensured that it goes to the neediest person.

Mr. Peter Kormos: That's what I was getting at.

The Chair (Mr. Bas Balkissoon): Thank you. We'll now move to the government side. Mr. Dhillon.

Interjection.

The Chair (Mr. Bas Balkissoon): Oh, Mrs. Albanese.

Mr. Vic Dhillon: Mrs. Albanese has a question and then I'll—

Mrs. Laura Albanese: Yes, first of all, I wanted to have a clarification. You spoke about 50 deaths worldwide. Is that within one year? What's the time frame?

Dr. Gary Levy: We do approximately, in liver—the question is related to living liver transplantation?

Mrs. Laura Albanese: Yes.

Dr. Gary Levy: We do approximately 50 live donor liver transplants per year, and as Mr. Markel said, at the moment, that number over the past several years has plateaued. Part of the reason is that—I wish I could tell you that all Ontarians are healthy. I could go around the room here and tell you which people I would accept as live donors; I'm not going to do that today. But Ontarians are not all healthy.

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One of the good pieces of news from this is that we actually impact the health of Ontarians through this program. We actually encourage them to live better lives through this. Many of them have their BMIs, their body mass index, go back to normal, and we predict that they'll actually do better than the average Ontarian.

Mrs. Laura Albanese: To go back to what Mr. Kormos was asking before: Typically, after you have, let's say, donated a kidney, and I guess that would be different from donating a liver, what types of changes in your lifestyle do you have to make? Do you go on living, let's say, the way you did before? Or do you have to take some dietary precautions, some other medical precautions, for the rest of your life, after you've been a donor?

Dr. Gary Levy: We encourage people to go back to living a normal life but a healthy life. So, I would argue, many people in Ontario are not living healthy lives, and we try to convince them to live healthy lives. If they do that, we believe that it's safe to proceed with living donation. If they go back to living unhealthy lives, I would argue that it probably isn't safe to do this.

Mrs. Laura Albanese: And that would be the case for a kidney donation and also for a liver?

Dr. Gary Levy: Liver is a little bit different because of the fact that it regenerates, and within 12 weeks, you have a full-sized liver. So as long as we keep a very close watch during those 12 weeks—but that doesn't mean that we encourage people not to live healthy lives.

The Chair (Mr. Bas Balkissoon): Thank you very much. We'll now move to the PC Party. Mr. Miller.

Mr. Norm Miller: Thank you for your presentation. You mentioned that we have the lowest deceased dona-

tion rate in North America here in Ontario, and I'm pleased to see you have a May 4 meeting to address that issue. But if you were going to list some things we could do to change that scenario, to increase the number of people donating, both the living and deceased donation rate, what would be the top items that you would recommend?

Dr. Gary Levy: You may or may not be aware that the minister has asked me to chair an expert panel on waiting times and access to transplantation in Ontario. I've struck a committee. Mr. Markel sits on that committee. We have experts from around the province—business leaders, health leaders, people from all walks of life. We have the dean of the northern medical school sitting on this committee.

I'm not at liberty to share the report, needless to say, because it hasn't been prepared and released, but I promise all of you that within about four weeks of the completion of the symposium, we will be submitting to the government a series of recommendations on how we believe we can improve the system here in Ontario. We hope that you'll all support it strongly.

Mr. Norm Miller: Thank you. I look forward to that. Bob, do you have any questions?

Mr. Robert Bailey: If I have a minute.

The Chair (Mr. Bas Balkissoon): You have half a minute. Go ahead.

Mr. Robert Bailey: Okay. I'm sure the answer to this is—we probably already know it. If you already had a pre-existing health condition, would that necessarily rule you out as a living donor? I suppose it would depend on what the condition was.

Dr. Gary Levy: You've partially answered the question. The decision is not a totally democratic decision. I've had people who have insisted they will be donors. We make the final decision, and it's based on the safety of the donor. So if we believe that your pre-existing health issue will not impact your health, we'll proceed. If I and my colleagues believe it will, you cannot proceed.

Mr. Robert Bailey: Thank you.

The Chair (Mr. Bas Balkissoon): Thank you for taking the time to be with us.

CITIZENS PANEL ON INCREASING ORGAN DONATIONS

The Chair (Mr. Bas Balkissoon): The next presenter is Ted Boadway, chair of the Citizens Panel on Increasing Organ Donations.

Dr. Ted Boadway: Thank you, Mr. Chair. My name is Dr. Ted Boadway. I was privileged to be the chair of the Citizens Panel on Increasing Organ Donations. I'm comfortable to speak on behalf of my fellow panel members. They were Alvin Curling, Peter Desbarats, Reverend Brent Hawkes, Gisèle Lalonde, and Senator Joan Neiman. They're all famous enough that I'm sure you know who they are. And for my sins, I was asked to be chair by Mr. Smitherman.

We submitted our report in March 2007, so that's been available in the public domain for a long time.

When we were doing our work, we held dozens of public forums right around the province and we had a great deal of survey work done for us as well. It also kind of took over our private lives, in that because people knew we were on this panel, every social situation, family situation and business situation got turned into a discussion on organ donation, and actually, we didn't mind that because it all turned out to be very valuable input. It was a very rewarding thing to do, because what we discovered is that many people in this province had thought deeply about this subject and were intensely interested in it and wanted to express their wisdom—and it was wise. Living donation was always a point of particularly intense, focused discussion. When people thought about this, it was really intense, and I think part of the reason was that they put themselves in the shoes of someone considering being a living donor and they wondered whether they themselves would be willing to do that. Most people thought that if the attraction of affinity was close enough, if it was a relative or a loved one—but when you started talking about anonymous donors, people really began to think that perhaps they wouldn't do it. They wondered if they would even do it if it were a relative. So people really had to look inside, and I think that's one reason they were so interested in talking about it. They held people who had been living donors almost in awe when they discussed it. They wondered how people got to that spot and how it had affected them and what was going through their minds. They wanted to hear about it. Sometimes we had a living donor there who could talk about it; most often, we didn't. We also heard from people who wanted to be living donors, or who had considered it deeply and perhaps were in the process or had decided they wouldn't be.

When we talked to folks everywhere across the province, they had it figured out. They knew that giving a solid organ was a major procedure that should not be undertaken lightly. They knew that there would be a significant convalescence for that person and that there would be a period of being unwell. They knew that it would be a life-changing event for the person who gave, just as it would be for the person who received. They would very quickly get to, not only are there emotional and physical costs to the person, but there are real financial costs, and what are those costs and how does that work out? They had a bunch of questions. Or maybe they thought it would cost X, Y and Z, because they had thought it out. Then they would often get to the point of asking, "Costs aside, what would happen if I lost my job?" Here they've done this wonderful thing that's so altruistic, and they lose their job. Boy, what kind of a situation would that be for a person?

So we found that they were very interested in this topic and wanted very quickly to switch to what we could do about it. After they'd articulated it, they asked, "What can we do about this?" What they said universally is,

"We should support these folks." When we were doing our panel work, it was just like all other things when you're dealing with people—people aren't unanimous. This is something on which there was unanimity. Absolutely 100% of people said, "We should support these folks." It really surprised us to find that degree of unanimity on anything, and there it was. We couldn't find nays to that proposition. In this situation, the PRELOD is already in. That was one of the things we recommended; that is, income and expense supplementation for people. No one is going to get rich on it, folks, if you ever look at the terms, but at least they won't be out of pocket so badly when they come to do it. And the other essential part of looking after these folks is making sure that when they come back, they have a job to go to. It's fundamental to our personal economy to make sure that we don't have too many expenses we can't recover if we go and do this; even more fundamental is being able to return to work. If we don't have that, our family's economy is truly torched.

This bill is about job security. It is what we recommended at the time. We're very pleased that the government of Ontario has decided to undertake this. We're glad you're giving it serious consideration, and we look forward to its implementation.

Living organ donation is something that people are willing to think about. Some will consider doing it; many people, after looking into themselves, will not. On the other hand, if we put barriers in the way, we make it less likely that people will be willing to, and they are the people who deserve our support above all.

1340

The Chair (Mr. Bas Balkissoon): Thank you. We have about two and a half minutes from each side for questions. Mr. Dhillon.

Mr. Vic Dhillon: Thank you, Mr. Boadway, for your presentation and for your work. In your opinion, could you maybe explain if there will be an increase in donations by living donors with the job protection that we're offering?

Dr. Ted Boadway: I can only give you an answer from what we heard. We heard from people who said, "I have a situation in my family"—or affinity relationships—"where I would be willing to consider it, but I can't because I'm worried about my job security." We've heard that from people. When it actually comes time to do it, people go through another complex set of thoughts in their mind, and you can't guarantee that that will actually result in activity. I don't know of any way to tell you how you would predict or what the statistics would be on it. All I can tell you is that we actually heard from people who said, "I will give it serious consideration. I think I will do it if I have a guarantee of a secure job to come back to." Only time will tell whether that plays out.

Mr. Vic Dhillon: Thank you very much, again, for taking the time and for all your work. This is such an important issue.

Dr. Ted Boadway: Thank you.

The Chair (Mr. Bas Balkissoon): We'll now move to the PC party. Mr. Miller.

Mr. Norm Miller: Thank you for your presentation, Mr. Boadway. Just for clarification, the PRELOD program is in effect now, is that correct?

Dr. Ted Boadway: It's running.

Mr. Norm Miller: So that covers some expenses and some income loss.

Dr. Ted Boadway: Yes.

Mr. Norm Miller: Okay. I think we're all supportive of this initiative and this bill and we hope it makes a bit of a difference, but it seems to me that there are still the great masses of people out there. A lot of them either don't think about organ donation or they're just not conscious or they don't know how to do it. We just heard from the previous presenter that we have the lowest deceased donation rate in North America. Are there other things that came from your report that you would recommend be done to try to change that number?

Dr. Ted Boadway: We actually put quite a complex series of recommendations in the report, which were related to what we can do with the public, what we can do with changing some of our laws to facilitate it, what we can do in hospitals, and what we can do with health professionals. We think there are a whole bunch of areas that each have to be addressed. No one can guarantee that if you actually do any one of those just right, you'll have the effect we would all love and would dearly wish. In fact, I don't think any one will do it. I think you have to approach it as a broad spectrum issue. You have to see what you can do in each one of these areas, and I think that, quite frankly, some of them are being ticked off as we go along. As I say, only time will tell if it's really going to work.

Mr. Norm Miller: Is there any jurisdiction in the world that is the reverse of us, that is the best example of a country or an area that is very successful with living and deceased donation rates?

Dr. Ted Boadway: One of my pet peeves, by the way—so I'll answer it this way. We heard about the wonders and the marvels of other jurisdictions, and I think you have to be very careful when you hear that. The reason you have to be careful is that when we actually looked into those other jurisdictions, we found that things weren't exactly as represented to us sometimes. Sometimes they kept their statistics differently, so that if they kept the statistics the way we do, they might have lesser rates than we do. Sometimes they had very different demographics among their population, so that, quite frankly, they had far more donors available, and the fact that they only had that many donors is a disgrace; they should have had more, because they're killing more people, for example. So I found that trying to look at other jurisdictions and saying, "They're perfect," was a futile exercise. What we decided to do instead was look at other jurisdictions for best practices, and we borrowed shamelessly. Those are in here.

The Chair (Mr. Bas Balkissoon): Thank you. We'll now move to Mr. Kormos.

Mr. Peter Kormos: I wish I had had more time with Dr. Levy. Do you have any sense of the profile of anonymous living donors?

Dr. Ted Boadway: None.

Mr. Peter Kormos: Is there a profile?

Dr. Ted Boadway: I can't tell you. I don't know.

Mr. Peter Kormos: I wish Mr. Markel was here, because I'd ask him—maybe you can help. In terms of this marketing towards young people, and I found young people—

Dr. Ted Boadway: I'm willing to cede a minute of my time. No problem.

Mr. Peter Kormos: Okay.

Dr. Ted Boadway: Frank, come on up.

Mr. Peter Kormos: Yes, please, because this focus on young people—just my sort of informal experience is that high school kids, college kids are more than willing to talk about organ donation and tend to be very gung-ho about the proposition. So I don't quarrel with identifying them as potential donors. Obviously, you're not talking about them necessarily being a donor as a young person; you're talking about them being part of the donor movement, if you will, all of their lives.

If you identified—again, are there age areas, are there other areas where people are more likely or less likely to be active donors, and that is to say, to actually do a donor card in the system that we have now?

Dr. Ted Boadway: You can answer that better than I can.

Dr. Frank Markel: Yes, I can answer it. Dr. Levy referred to it in his comments. There's a considerable differential in consent rates. The statistics I'm going to give you are the consent rates of families who had a loved one who had died and was actually in the situation and could be a donor. Across the province of Ontario, the overall average consent rate is 60%. Six families out of 10 say yes in the situation. In Toronto, it's four out of 10, and in the rest of the province, it's eight out of 10.

Mr. Peter Kormos: That's interesting, isn't it?

Dr. Frank Markel: I think it's very interesting. We have some data—it isn't data we could publish—looking at the consent rates by ethnic background. There's a considerable difference between people of European background and others. To a considerable extent, when you look at the ethnic makeup of Toronto, that explains the difference.

That's why, in particular, we have pushed on this multi-faith approach. There are misconceptions in the Jewish community, in the Muslim community, that their religious beliefs do not allow them to be donors, despite the fact that religious leaders in both communities affirm the support. That's part of the challenge we face, particularly in Toronto.

Mr. Peter Kormos: Okay. Thank you kindly. I appreciate your letting Dr. Markel come up here.

Dr. Ted Boadway: No problem—needed information.

The Chair (Mr. Bas Balkissoon): Thank you very much.

STEWART STARK

The Chair (Mr. Bas Balkissoon): The next presenter is Stewart Stark, Human Resources Professionals Association. Welcome. State your name for the record. You have 15 minutes. In whatever is left over, there will be questions.

Mr. Stewart Stark: All right. I don't think I'll be that long. Thank you, Mr. Chair and members of the committee.

My name is Stewart Stark. I'm employed by the Human Resources Professionals Association, but I'm here as an individual and as an organ donor to talk about my experience with organ donation.

In late 2001-02, my father's liver started to deteriorate due to cirrhosis of the liver. He was put on a donor list at that time, once it was determined that he needed one. Then, in early 2002, the option was brought to me to be a living donor, which I immediately said yes to. You don't really think about it; you just do it.

On June 6, 2002, I successfully donated 70% of my liver to him. I was told at the time, or leading up to it, through all the tests, that I'd be off work for probably between six and eight weeks. But I was very lucky in that I ended up being off for only about three and a half weeks. I was in hospital for about a week, and then for about two, two and a half weeks, I was recuperating at home.

I really like this bill for the simple fact that—when I was talking to my father about this, obviously there were concerns from him about my health and what might happen to me. I'm very healthy; I recovered very quickly, so that wasn't an issue. Obviously it was a concern of his. But at the time, I was 22 or 23. It was very early on in my career, and that was a real worry for him, taking this time off, potentially six to eight weeks from my employer, and how that was going to go. Again, I was very lucky in that respect. I was given two weeks off paid, and then I had to apply for EI, and basically by the time I applied for EI, I was coming back to work.

That's really all I have to say about that. That was my experience.

1350

The Chair (Mr. Bas Balkissoon): Thank you very much.

Mr. Stewart Stark: You're very welcome.

The Chair (Mr. Bas Balkissoon): We'll go to questions now. Mr. Miller, you have about three minutes.

Mr. Norm Miller: First of all, thank you for your presentation, for bringing your personal experience to bear on this issue.

Mr. Stewart Stark: No problem.

Mr. Norm Miller: In your case, it was obviously your father, so it was—prior to this experience, had you thought about organ donation at all?

Mr. Stewart Stark: I really hadn't, up until even after my father got sick and was put on the list. They have a policy: The person who needs the organ can't directly ask you; it's brought up. I guess it's a moral thing. Really, up

until that conversation, I didn't really—I'd heard of it, I'm sure. I'd maybe given it a passing thought, but I hadn't really thought of it in this situation.

Mr. Norm Miller: Had you thought about the deceased—did you sign your driver's licence, that kind of thing?

Mr. Stewart Stark: No. No, I hadn't even done that, to be honest with you.

Mr. Norm Miller: I think there are lots of people out there who are like yourself and hadn't thought about it.

Mr. Stewart Stark: Absolutely.

Mr. Norm Miller: In fact, I think I've signed my driver's licence, but I'm going to check the Trillium Gift of Life website to make sure I'm registered to donate organs. Do you have any suggestions on what you think we can do to make more people aware of organ donation?

Mr. Stewart Stark: Of my close family and friends, I'm the only person I know who has done this. I have had a chance, obviously, to meet a lot of people who have since, but everybody is interested in it. Everybody wanted to know. As an organ donor, you tend to downplay it a lot because it was three weeks, and I felt fine afterwards. I've talked to other donors, and everybody downplays it. Everybody else thinks it's a great big deal, but I guess you need to be humble about it. Everybody wanted to know about it, and at the end of those conversations, I would usually ask, "Have you signed your donor card?" They would usually say, "I haven't even thought about it," but in most cases, they would now.

Mr. Norm Miller: Yes. Mr. Klees and also Mr. Kormos had private members' bills to do with trying to get more people to think about it. In Mr. Klees's case, if you applied for a health card or a driver's licence, you would have to check off a box, "yes," "no" or "don't know." You had to make a choice anyway, and I think that's a good idea so that at least people at one moment in time think about it and make a decision. Then you can have a registry from that where you know the people who are willing to donate.

Mr. Stewart Stark: It's all about having a conversation about it, bringing it up and also knowing somebody. Obviously, everybody isn't going to know Somebody else: in the situation, but I think as soon as it touches a little closer to home, people will give it more thought, give it more serious thought. To this day still, before people ask how I am, they ask how my father is. It has made a big difference.

Mr. Norm Miller: Thank you.

Mr. Stewart Stark: You're welcome.

The Chair (Mr. Bas Balkissoon): Mr. Kormos.

Mr. Peter Kormos: How's your dad?

Mr. Stewart Stark: He's very well.

Mr. Peter Kormos: It's interesting. If I was told by my doctor that I needed a liver, I'd have to get my brother over to the house somehow, maybe get a few drinks into him and—

Interjections.

Mr. Peter Kormos: Well, no, seriously.

Mr. Stewart Stark: Probably not if you needed a liver.

Mr. Peter Kormos: And you just sort of casually say, "Oh, by the way, it would really be nice if I could get your liver"?

Mr. Stewart Stark: You've got to bring it up in a way that isn't really asking. The way it happened for me was that my parents sat me down and said, "This is an option." As soon as they said, "This is an option," a light bulb went off, and I said, "Okay, let's do it. Let's start the testing."

Mr. Peter Kormos: Fair enough, but did they get direction from the medical staff who were supervising your father?

Mr. Stewart Stark: I believe they did, yes.

Mr. Peter Kormos: We read in the paper—was it today?—that how the organ is requested of the deceased's family makes a big difference in whether or not that family—of course, we're talking about dead donors. But is this direction given by way of advice? You don't want to extort organs out of people.

Mr. Stewart Stark: Absolutely.

Mr. Peter Kormos: Because they're a loved one, you don't want to make them sort of—extort. Was that the basis of the counsel that your father got, that this is a fairer way of asking than outright asking?

Mr. Stewart Stark: I believe so, yes, because they did mention to me afterward, "We can't ask like this." I believe my mother actually said that during the conversation. She said, "We can't ask you to do this. We just need to bring it up and make you aware of this option." I'm assuming that the doctors they were dealing with at Toronto General advised them on that.

Mr. Peter Kormos: That's interesting. I can be so incredibly obtuse sometimes and miss the point and miss the point and miss the point. Then I'd end up going home and three days later I'd go, "Wait a minute. I think...." Okay, that's interesting. That's a great story.

We're on to the levels of discomfort and so on. It hurts, I suppose? I've never had surgery. I had my appendix out when I was three years old, but I've never—

Mr. Stewart Stark: You'd better knock on wood.

Mr. Peter Kormos: So it hurts?

Mr. Stewart Stark: I've got a scar kind of coming down like this. I was in the hospital for a week. For the first three or four days, I was way too out of it to feel anything.

Mr. Peter Kormos: On morphine and stuff?

Mr. Stewart Stark: I was on just about everything at the time. Then afterwards, actually, the only discomfort I had was that the nurse happened to give me blood thinner in the same arm instead of switching it up. That wasn't even part of the actual surgery. Other than that, it really wasn't that sore. It heals up. You know, it's uncomfortable. It gets itchy, but it's not pain. It's just discomfort.

Mr. Peter Kormos: Is there any sensation that you've had at least, what, half your liver taken?

Mr. Stewart Stark: No, and by the time you're back to 100%, your liver is almost regrown.

Mr. Peter Kormos: Foie gras.

Mr. Stewart Stark: It takes between six and 12 weeks to regenerate. Now, apparently, I did get better a lot more quickly than most people had in my position.

Mr. Peter Kormos: Thanks for coming here today. I appreciate it.

Mr. Stewart Stark: You're very welcome.

The Chair (Mr. Bas Balkissoon): Thank you very much for coming and sharing your situation with us.

Mr. Stewart Stark: You're very welcome.

Mr. Vic Dhillon: Chair?

Interjection.

The Chair (Mr. Bas Balkissoon): Sorry. I forgot the government side. I got taken up with Peter. My apologies to Mr. Dhillon.

Mr. Vic Dhillon: Thank you very much for everything, for your courage and coming here. It really means a lot.

Mr. Stewart Stark: You're very welcome.

Mr. Vic Dhillon: My question is, what impact would providing job-protected leave have on living donors? Would they tend to be more positive in terms of making that decision?

Mr. Stewart Stark: I really believe they would, and as I said, it's—I can only speak for myself, but when you decide to do this, everything else becomes secondary to a certain extent. You still have to worry about your life, but you're more worried about the person you're donating to being comfortable with it. I've talked to quite a few donor recipients, and they get a little stressed out, and they worry about this loved one who's in great health who then has to go under the knife and go through this procedure, so they're always thinking of them. This not only puts the donor at ease, but it puts the recipient at ease, which, in a way, further puts the donor at ease, and everybody kind of feels better about it. I hope that made sense.

Mr. Vic Dhillon: Sure. Do you feel that 13 weeks is enough time? I know you mentioned you recovered much earlier than the average. Can you give us some comments on that?

Mr. Stewart Stark: I can only speak about the liver and myself, obviously. I think 13 weeks is a good amount of time, but again I can only speak about the liver. I don't know how it is for other organs and how long the recuperation time is.

Mr. Vic Dhillon: Good. Once again, on behalf of the committee, thank you very, very much for everything you've done.

Mr. Stewart Stark: Thank you very much for having me.

The Chair (Mr. Bas Balkissoon): Thank you very much again.

1400

SUBCOMMITTEE REPORT

The Chair (Mr. Bas Balkissoon): That's the end of deputations. We have a report of the subcommittee on committee business. Mr. Delaney.

Mr. Bob Delaney: Your subcommittee met on Wednesday, April 8, 2009, and agreed to the following:

(1) That members of the Standing Committee on the Legislative Assembly and two staff attend the 2009 annual meeting of the National Conference of State Legislatures, subject to approval by the House.

(2) That the subcommittee be authorized to approve a committee budget for the delegation attending the NCSL annual meeting for submission to the Speaker and the Board of Internal Economy for their approval.

The Chair (Mr. Bas Balkissoon): Thank you very much. Shall the report of the subcommittee be adopted?

Interjection: Carried.

The Chair (Mr. Bas Balkissoon): That carries.

Mr. Peter Kormos: Chair?

The Chair (Mr. Bas Balkissoon): Can I just make two short announcements and then I'll come back to you?

Mr. Peter Kormos: I want to speak to this, Chair.

The Chair (Mr. Bas Balkissoon): Oh, this one? Okay. Sorry, go ahead.

Mr. Peter Kormos: Mr. Miller and I were at the House leaders' meeting this morning, and in a rare moment of generosity, I proposed that that wasn't an inappropriate proposal, especially if newer members of the Legislature tend to go on these, because they can, if people are disciplined, be good learning experiences. But the government raised concerns about two staff members. I, quite frankly, deferred to the committee. I said, "Here's the committee's request." Some of you may know I believe very strongly that committees should control their own process as much as possible. The committee made a decision for two staff people. I was told—and I'm not sure how valid it was—that the precedent is one staff person. I'm not sure if that's necessarily a hard precedent when you've got nine committee members going, because staff people learn things too, right? We're talking about people from the clerks' office, I presume, amongst others. So perhaps the committee could talk about that so we can persuade the government not to be so niggardly in terms of just one seat.

The Chair (Mr. Bas Balkissoon): Mr. Delaney?

Mr. Bob Delaney: Chair, I agree with Mr. Kormos. In the two such events I've attended, the presence and the contribution of both staff members was absolutely invaluable for ensuring that for the delegates attending, the process of moving through the convention was smooth, that we were able to meet and effectively work with members of other state and provincial Legislatures. I think the presence of both staff members, on both occasions that I've attended this convention, has been full value for the dollar, and I've observed particularly how our clerk has worked very hard throughout the event.

The Chair (Mr. Bas Balkissoon): Mr. Miller, did you have a comment?

Mr. Norm Miller: Sure. I don't know what the precedent is, whether it was just raised by some government members. They seemed to think it was one, not two, staff members, although, as I recall from last year's conference, the staff member was actually participating, I

believe, in putting one of the seminars on, to do with the way the Ontario Legislature records its Hansard and all the various treasures in our library on to digital form. But perhaps you could let us know what the standard is or if there is one. Otherwise, I'm fine with two.

Mr. Peter Kormos: This is stupid to talk standards, precedents. First of all, I don't believe it's a precedent, and Mr. Delaney's just confirmed that. Secondly, the committee should control its own process in that regard.

Now, who are the two staff people who are contemplated attending?

The Chair (Mr. Bas Balkissoon): The clerk and the procedural clerk went the last time, right?

Interjection.

The Chair (Mr. Bas Balkissoon): So it'll be the clerk and the procedural clerk, the research officer.

Mr. Peter Kormos: These people not only assist members during their attendance, as Mr. Delaney has said, but they undoubtedly interact with their counterparts, because other teams of delegates have brought their staff people along. This isn't just a politicians' event; it's something that the civil servants and bureaucrats, amongst others, can derive benefit from too.

So I hope the committee can just be very clear in that it's asking for two staff. It has been, at the very least, the recent history of the committee that those two staff persons have been valuable to the committee members who attend, and that they, in and of themselves, bring back a whole lot of stuff.

The Chair (Mr. Bas Balkissoon): I hear you loud and clear. Thank you for your comments. The committee did carry the report.

I just have two quick announcements. I want to remind you that the deadline for filing amendments is Monday the 27th, at 3 p.m., and on Wednesday, from 1 to 3, we'll be doing clause-by-clause.

Thank you very much. The committee's adjourned.

The committee adjourned at 1405.

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