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Mercredi 4 février 2004

Standing committee on general government

Health Information Protection Act, 2003

Comité permanent des affaires gouvernementales

Loi de 2003 sur la protection des renseignements sur la santé

Chair: Jean-Marc Lalonde
Clerk: Tonia Grannum

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ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON GENERAL GOVERNMENT

COMITÉ PERMANENT DES AFFAIRES GOUVERNEMENTALES

Wednesday 4 February 2004

Mercredi 4 février 2004

The committee met at 1006 in Howard Johnson Confederation Place Hotel, Kingston.

HEALTH INFORMATION PROTECTION ACT, 2003

LOI DE 2003 SUR LA PROTECTION DES RENSEIGNEMENTS SUR LA SANTÉ

Consideration of Bill 31, An Act to enact and amend various Acts with respect to the protection of health information / Projet de loi 31, Loi édictant et modifiant diverses lois en ce qui a trait à la protection des renseignements sur la santé.

The Chair (Mr Jean-Marc Lalonde): Ladies and gentlemen, on behalf of the standing committee on general government, I'd like to welcome you all to our hearing on Bill 31. This morning we have four groups.

KINGSTON GENERAL HOSPITAL HOTEL DIEU HOSPITAL

The Chair: The first presentation will be from the Kingston General Hospital and the Hotel Dieu Hospital. I would ask the people representing those two hospitals to come up.

Thank you for taking the time to come and explain to us your concerns and comments that you have on Bill 31. You will have 20 minutes, which can be divided. If you're taking the 20 minutes, then there is no time left for question period. If there is time left, it's going to be divided amongst the three parties. Go ahead.

Mr Neil McEvoy: Thank you, Mr Chair. We do appreciate the opportunity to speak to you. My names is Neil McEvoy. I'm associate executive director of Hotel Dieu Hospital.

The acute care hospitals in Kingston are actually closely integrated in many ways. Among them is the management of personal health records for our patients, so the submission that we are bringing before you today is in fact a joint submission of Hotel Dieu Hospital and Kingston General Hospital, which as of January also includes the Kingston Regional Cancer Centre.

Behind me I have a number of members of our delegation, representing both hospitals. If my memory will serve me well—I haven't had a chance to make my notes to myself here—behind me we have Fran O'Heare, who is director of risk management at Kingston General Hospital; Paul McAuley, who is director of information management at Kingston General Hospital; and Karen Hanewich, who is the privacy officer at Kingston General Hospital. My colleague to my right, Karen Humphreys Blake, will perhaps have other introductions later on.

The Kingston hospitals actually have a long history of collaboration and shared services.

Our hospitals have a long tradition of co-operation. We have always sought ways of rationalizing the services in our region for obvious reasons: We would like to avoid duplication, improve efficiency of our services and, in particular, focus the resources that we have on the needs of our patients.

In this process, the health records department has long been a very strong and obvious candidate for this type of integration. In addition to the economies that we can achieve by bringing together the management of two different groups, there are also very significant gains to be had in terms of patient care. Having all of the information for a patient available under one cover really assists greatly in the assessment of that patient and in the delivery of care.

Back in 1996, the Kingston hospitals took the innovative step of establishing a single patient identifier for the patients in this region who are treated in both hospitals. This effectively allowed us to bring together the records for all of these patients within one physical area and under one administration. We have been doing so ever since and we can confidently say that this has been a very positive move in terms of patient care. Our caregivers have appreciated the fact that they have available to them as much as possible of the information that is required for them to deliver care to the patients. It does involve the combination of both hospitals working in unison.

Our submission, therefore, will address the act insofar as it relates to shared medical record departments. I'm sure you have heard many submissions from others regarding some of the details of the act that is proposed. We will try to narrow it down to what we feel may be some expertise that we can offer in this area, since we have been doing this for upwards of seven years now.

We are grateful for the opportunity to appear before you and we want to reiterate that we share the values on which the legislation is based, those being to achieve the optimum balance between the needs of care deliverers in looking after the needs of a patient on the one hand, and on the other hand, preserving and protecting the privacy

of this information as it relates to the individual. We do realize that it is a delicate balance that we are looking for through the legislation.

We feel the framework that has been proposed in this legislation is commendable—it does strive to do this—and we wish to support it as much as we can. We would point out that many of the provisions of the act are in fact reflective of professional activities that have been followed and established by the professions within our organization. To bring these together under a single framework is certainly something we wish to do, but we are simply reinforcing many of the practices that have already been in place throughout our hospitals.

However, in integrating the personal health records across institutions, we think that we may be able to offer you some insights into some of the challenges that we may face, and we would suggest with respect that by looking at how this act might apply to an existing shared service in Kingston across the two hospitals, your committee may be able to determine how well this act or this legislation will in fact promote the integration of hospital services across the province. You are no doubt aware that hospitals are encouraged to integrate, to come together, to avoid duplication, not just in one city but across regions. We feel that this will be a trend over the next five to 10 years. The act, therefore, should not impede that. It should support it as much as possible without in any way impairing the rights of the individual. I hope that our comments and our suggestions will be along those lines.

We have three areas to suggest where improvement to the legislation could be contemplated.

First is that the role of physicians as agents or as custodians may need to be clarified. The setting in which health care is delivered in a hospital is really built around a team. Whether that team is delivering care concurrently or continuously, the access by more than one person to patient information really is vital to good patient care to the people who come into our hospitals.

A custodian under the proposed legislation may delegate to an agent the rights and accountabilities for collection, use and disclosure of information as they extend to the custodian herself. This means that a physician who is working as an agent will have access to the complete record of a patient that is available in the hospital. However, if the physician as a care provider is defined as a custodian, then those portions of the act that relate to the communication between custodians may limit the ability of the physician in any one hospital to have access to the complete record of a patient being seen in that hospital.

In a setting such as Kingston, where we have two hospitals in operation sharing a single record, this becomes a more complex relationship. So, for a physician operating in one hospital, we must consider whether that physician is an agent or a custodian with respect to the other hospital, where the other hospital has the custody of the physical record. I'll return to this with our third recommendation, but we do feel that the legislation itself would benefit from a clarification of the role of physicians and other independent caregivers with respect to the act.

Our second recommendation is that the legislation prescribe discrete portions of the health record for which consent may be withheld. The act appropriately recognizes the right of the individual to have certain portions of her health information withheld from distribution and disclosure. However, the implementation of this at a practical level will have consequence for hospitals. We have policies and procedures in place for the employees who handle records. These are agents of the custodian within the meaning of the act. The act does not specify the granularity at which consent my given or withheld. In the absence of some specification, we would need to establish fairly detailed procedures that could extend from whole sections of a chart down to individual pages. This would require documentation built in to our procedures so that the agents of the custodian would comply with the act and make sure that only those portions of the health record are withheld from disclosure to other custodians.

As you can imagine, this will entail the commitment of certain resources and will add complexity to the administration of the act. Our recommendation, therefore, is that the act or its regulations specify which discrete portions of the chart, of the patient record, may be identified and for which consent may be withheld. We are not suggesting that there be any portions of the chart for which consent would not apply, but simply that it be broken up into fairly discrete sections so that the administration of the act will be more realistically achievable.

Our third recommendation drives straight to the essence of shared services. We are proposing that the act or its regulations elaborate on the respective obligations and accountabilities of the many custodians who may act as one, as provided for in subsection 3(7). In those definitions of a custodian, it provides for the case where two or more custodians may apply to act as one custodian. This provision would apply, for instance, to our hospitals, where we share the collection, use and disclosure of patients' personal health information.

However, the success of this sharing rests very much on mutual trust and collaboration between custodians and between institutions. The act, as written, provides little guidance on how the respective obligations, accountabilities and delegations should be distributed. We feel this is important. The act itself does provide for a form as specified by the minister, but if we are to support the sharing of patient records among institutions, we feel that it would benefit from much greater thought as to how the responsibilities would be shared among the custodians.

As I mentioned under the first recommendation, when we have health care providers—physicians, for instance—operating in one institution with access to and the ability to disclose information that is under the custody of another institution, we must make sure that we understand which custodian is really responsible for any infractions of the act. It would be unfair to have one

institution, one custodian, with no authority over another custodian, subject to the requirements of the act or to the punitive measures of the act should there be an infraction. We feel that it would benefit the community at large if this portion of the act could be elaborated and further thought given to how the responsibilities and accountabilities would be shared.

Members of the committee, we thank you for the opportunity to bring before you these suggestions and these observations. As providers of health care, we are committed to the values and principles that you are. Also, as providers of health care, we rely on the generosity of our community. As partners in health care in this community, we would also like to address with you our concerns in the area of fundraising. With your permission, I wish to defer to my colleague Karen Humphreys Blake.

1020

Ms Karen Humphreys Blake: Good morning. My name is Karen Humphreys Blake. I am vice-president, public affairs and development for Kingston General Hospital and secretary to the board of directors of the Kingston General Hospital Foundation.

I note that Kingston General Hospital has recently joined with its partners in the provision of health care—Hotel Dieu Hospital, Kingston Regional Cancer Centre and Providence Continuing Care Centre—to establish a joint approach to fundraising in this academic health sciences centre. We have recognized the need to raise funds at a much higher level if we are to continue providing care to the more than 500,000 people in southeastern Ontario.

Thank you very much for allowing me the opportunity to address the committee as it relates to the fundraising component of the Ontario health privacy legislation.

With me today is Lee Macnamara, who is president of the KGH foundation, as well as other colleagues from KGH and Hotel Dieu.

Let me begin by saying that we are supportive of the introduction of this legislation that will protect the privacy of all Ontarians in matters that relate to health. We do, however, have a concern regarding the requirement for express consent to ask patients for their support. Many of these patients are very grateful and do want to provide their support.

At the Kingston General Hospital Foundation we have long practised privacy protection as outlined by the Association for Healthcare Philanthropy, the Canadian Centre for Philanthropy and the Canadian Association of Gift Planners.

Kingston General Hospital, as a tertiary care teaching hospital, must be available when local community hospitals need help dealing with complex, specialized patient needs. This means we must provide care above and beyond what our partner hospitals throughout the region can deliver. This means significantly larger capital commitments in equipment and technology to treat patients and educate future health care providers. We here in Kingston care for the most sick and injured patients from across southeastern Ontario.

We believe ethical and moral issues abound when considering asking patients at any time during their admission, or stay, to sign an express consent that allows the hospital to solicit financial contributions. Patients are not in a position to make a fair and informed decision when they may be in their weakest or most vulnerable state. Imagine yourself being brought to Kingston General Hospital by ambulance from Brockville, Cobourg or Bancroft and being asked if we can solicit you for fundraising—the farthest thing from your mind, I'm sure, and it should be.

Almost 50% of admissions to KGH are through the emergency department and, on average, 50% of patients in hospital at any time could be from outside Kingston, thereby creating additional challenges when we're seeking local support for services.

Caregivers often work in states of constant high stress and must be able to focus their efforts on their direct care duties and not be expected to become fundraisers as a regular part of their job.

There is no central discharge process, as people have varying outcomes that affect their method of release. Therefore, the discharge process does not provide a reasonable point for acquiring express consent for fundraising.

The express consent being proposed in Bill 31 is in conflict with what research in other centres has shown to be the public's view. People do not want to be confronted with express consent when their mind is on their health issues. In studies done on express consent at Mount Sinai Hospital in Toronto in 2001, 75 patient complaints were received in the first 90 days of the study compared to an average among hospitals of one to two complaints for every 10,000 to 20,000 mailings on fundraising.

Current practices at Kingston General Hospital include a grateful patient mail program with 20,000 to 30,000 letters sent out annually. Letters are sent out by the hospital asking for support through the hospital foundation. Foundation and development office staff have no direct access to patient information. It is only when patients become donors that further requests are made by the KGH foundation.

KGH follows the suggested grateful patient program guidelines as outlined by the Association for Healthcare Philanthropy. All letters from the hospital and the foundation include an opt-out clause that will prevent future mailings at the patient's request.

The current practice allows us to carefully filter out those patients who would not be appropriate to ask based on the treatment provided or the outcome of their health situation. Express consent does not necessarily offer the same level of screening. We receive very few complaints, fewer than five per year.

While the amount of revenue derived from our grateful patient mailers is a small percentage of our overall revenue—about $20,000 to $30,000 per year out of a total of $1.8 million—it is often these donors who in later years become loyal, committed supporters as a result of being well served by their hospital.

I wish to point out that those people who start out by making small annual contributions as grateful patients are often the same generous people who make a thoughtful decision to leave KGH, and likely their own community hospital, in their estate plans. This adds up to millions and millions of dollars over the years.

These are the donors who provide the base for our future philanthropic success. Once an individual or their family member is touched by the health care system, they gain an appreciation for the quality of care that is provided when they need it most.

Kingston General Hospital is facing capital equipment requirements of over $30 million, infrastructure needs of another $30 million, and houses a research centre that is only in its early growth stage. Our health care partners also have significant short-term capital needs. This does not include restructuring costs that will be in the range of $60 to $70 million or more as we move forward. We desperately need every dollar that is available from residents across southeastern Ontario.

As I noted earlier, KGH is currently engaged in a joint initiative with its health care partners, Hotel Dieu Hospital, Kingston Regional Cancer Centre and Providence Continuing Care Centre in Kingston to build the infrastructure to take fundraising efforts to much higher levels in an effort to respond to the tremendous demands on our system.

In a world of increased financial accountability, transparency and efficiency, the proposed legislation will shift the focus from increased patient care through philanthropy to endless explanations as to why we have invest significant resources to put the "ask before the ask."

Bill 31 imposes much stricter limitations on hospitals and health care providers than charitable organizations in other sectors such as universities and the arts. If hospitals are going to be unfairly disadvantaged from seeking support from their grateful patients, my question to you is, where is the funding to come from to replace lost revenue? What plan is in place to offset this negative impact?

I was most pleased to read in the federal throne speech that strengthening the good work of the voluntary sector and supporting philanthropy has been highlighted as important for the federal government. I can only assume that strengthening this sector is also important for the Ontario government.

In conclusion, we ask that you seriously consider a revision to the proposed legislation that will allow an opt-out option for fundraising purposes rather than express consent for hospitals.

Thank you for the opportunity to share our views with you today.

The Chair: Thank you. We have one minute left. Last night we finished with the opposition, so it is the NDP's turn.

Ms Shelley Martel (Nickel Belt): I appreciate your points on fundraising; I think you're right on. We're going to need an amendment to this; we really are. The point I wanted to go back to has to do with the lockbox provisions. On page 2 you talked about the act specifying that consent may be withheld in respect of certain "discrete portions of the health record." Can you give the committee an example of what you mean by that?

Mr McEvoy: The areas that in our experience tend to be most sensitive are areas of the health record that may relate either to mental health issues or to infection issues. In both of those instances there may be portions of the chart, such as the records of an interview or the findings of an assessment, with which the individual may have some difficulty. Our concern is that if one page were to be removed or to be identified as having consent withdrawn from a much larger package of let's say a mental health assessment, searching for that page might be difficult. We would recommend instead that if there are issues within the mental health component or the infection component of the chart, that would be a quantum to identify for removal or for withdrawal of consent. When we talk of discrete components, we are talking of fairly well identified portions of the chart that could be identified in our policies and procedures so that if someone were to withdraw consent for one portion of that, that section be identified.

1030

The Chair: Thank you. The government side.

Mr Peter Fonseca (Mississauga East): This question will be around the fundraising. You did bring up that it is a very small percentage of your overall fundraising, the $20,000 to $30,000 that you get from direct asking of patients. Does that increase, with time, by much? How much of the $1.8 million, your overall fundraising total, comes from corporate donations or other donations?

Ms Humphreys Blake: I guess I did explain that it does increase over time. What we find is that once a donor becomes a donor, they might start with a small donation and then year after year the donation grows. It may be that they start with a $50 donation, and then it might go up to $500 or $1,000. Those people are also the ones who are very likely to include us in a bequest as they plan in terms of their estate. So it is significant. It's hard to measure. We'd have to track a number of them and we haven't had the ability to do that.

Mr Fonseca: I guess we'd like that tracking to know. It looks like it's making up about 1%—

The Chair: Time is up. Sorry. We're going to go the official opposition side.

Mr Jerry J. Ouellette (Oshawa): Thank you for your presentation. Just to expand—I know we don't have much time: You specifically stated, when you were talking about the physicians and the agents and the custodians, that there should be other caregivers who should be defined in there as well. Could you let us know which other ones you might be referring to?

Mr McEvoy: The act should apply to other practitioners such as nurse practitioners or other people who may have privileges, midwives who have privileges in a hospital; our language was intended to be inclusive of anyone who might be identified under subparagraph i of paragraph 3 of subsection 3(1).

The Chair: Thank you very much for your presentation today and also about your concerns.

HIV AND AIDS LEGAL CLINIC ONTARIO

The Chair: The next group is the HIV and AIDS Legal Clinic Ontario. Thank you for taking the time to come over and giving us your concerns. If we could have your name and position, please.

Ms Ruth Carey: Good morning. My name is Ruth Carey. I'm the executive director of the HIV and AIDS Legal Clinic Ontario. I'm a lawyer. I was called to the bar of Ontario in 1993. The legal clinic is a community legal aid clinic pursuant to the Legal Aid Services Act. We're primarily funded by Legal Aid Ontario. We're also funded in part by the Ministry of Health and Long-Term Care through the AIDS Bureau program.

I don't think it should come as a big surprise that the constituents I serve, the people living with HIV, in this province are concerned about the legislation. We have actually been involved quite actively in privacy consultations since 1997. I think this is probably the tenth government consultation I've been involved in. In my personal capacity, I'm also a member of the Ontario Advisory Committee on HIV/AIDS, which advises the Minister of Health and Long-Term Care on HIV legal issues and other kinds of HIV issues.

Some people may not know this, but just to make it clear, the reason that HIV-positive patients are so concerned about privacy issues and about this legislation is because HIV-positive patients are the ones who lose badly when their HIV-positive status is disclosed without their consent. My office handles between 200 and 250 calls every month from the HIV population in this province about things exactly like this. People get evicted from their buildings because their landlords find out they're positive. People get shunned by their families when their families find out they're positive. They get dropped by their friends. They lose their jobs. For a lot of these things, there are no legal remedies.

HIV-positive people are also the subject of the law. There are specific laws and procedures that make them an object of the law that make them feel even more stigmatized than they are by their communities. So, as a patient population, the HIV population in this province is probably more concerned about this legislation than any other population you can speak to.

On the other hand, HIV-positive patients are also frequent users of health care and, as a result, have a vested interest in ensuring that the health care system is there for them and that it works efficiently. So we see both sides of this kind of debate.

I'd like to focus, in actual fact, on four specific things in the legislation. I could probably talk for several days about this, but just to keep it down, the four specific things I'd like to talk about are the scope of the legislation, the permitted disclosures without consent, access to one's own records and the remedies that the legislation provides for a breach.

In terms of the scope of the legislation, from the patient's perspective, whether it's a hospital that has your health information or your employer, and whether or not that information gets disclosed without your consent, it doesn't really matter. From the patient's perspective, the harm is the disclosure to the person. So from the patient's perspective, hiving off the health industry in separate legislation is not a practical thing to do. From the patient's perspective, it would be better if Ontario's legislation covered the entire private sector.

At one point, one of the Conservative proposals on the table that we responded to was that there be broad, overreaching, single-framework legislation where there would be schedules for each sector, including the health care sector. To us, that was more patient-oriented; it made more sense. One of the things that's going to happen to patients if Bill 31 is passed is that they're going to be really confused about their rights and remedies in different sectors. If you're not covered by Bill 31, are you covered by PIPEDA? The ministry has assured me on more than one occasion that they seek exemption from PIPEDA. They seek to have Bill 31 declared as being substantially similar. Our position, quite frankly, is that it cannot be declared to be substantially similar because it only applies to the health care sector. PIPEDA applies to the broader private sector and it covers information other than health information. We simply are not in agreement with the ministry that they will obtain that exemption. So from the patient's perspective, this scope problem is problematic.

I would also point out that you have this wonderful purpose clause in Bill 31, which I completely agree with. The problem with it is that because Bill 31 is only about the health care sector, the purpose, as stated in section 1, will not be achieved, because health care information is in the hands of insurance companies, it's in the hands of employers, it's all over the place. So the purpose clause in fact will be defeated by the narrow scope of this legislation.

I'd like to talk now about disclosures without consent. You'll note I talk fast. I'm sorry, but I want to get my 20 minutes of fame in. I'd like to start with clause 37(1)(c). Clause 37(1)(c) permits the disclosure of personal health information for the purpose of contacting a relative or friend of a patient if the patient is unable to consent personally. I assume that this clause is intended to ensure that a custodian is able to try to find a substitute decision-maker when an individual is unable to consent to medical procedures on their own. If that's the purpose of the clause, great. I have no complaint with that whatsoever. But that in fact is not what the clause says. It says the custodian can call up any relative or friend for any reason whatsoever just for the purpose of contacting the relative or friend. There seems to be something missing. I would suggest a rewording of clause 37(1)(c) to read something like "for the purpose of locating a substitute decision-maker by contacting a relative."

There are a number of limited lockbox provisions in Bill 31, starting with clause 37(1)(a). It's not a true

lockbox, it's a modified one. From the perspective of people living with HIV, the idea of a modified lockbox is actually a good thing. It's very common for physicians treating people with HIV to have to refer them to other care providers for other kinds of care. It's very common for minor surgical procedures like hernia repair, stripping of varicose veins, the setting of broken limbs. In that context, one's HIV status is actually totally irrelevant. From the perspective of the person with HIV, it would be nice to have the option of being able to be referred to another physician for one of those procedures without having to go through the fear and the worry of being rejected by the new care team when your status is disclosed.

Don't get me wrong; that happens every day. I can tell you dozens and dozens of stories of nurses refusing to care for patients in their hospital who are HIV positive; of physicians being taken aback by the fact that they've suddenly found they're faced with an HIV-positive patient and saying, "Oh, I need to reschedule you so I can put in different procedures," as if they were some sort of Typhoid Mary for whom different procedures have to be put in place. It happens every day in this province. It's just because of the stigma that's attached to the disease. Over time, that stigma is decreasing, hopefully, but nonetheless it does exist. From the perspective of the patient who has experienced this personally, having the option of the partial lockbox is a good thing.

1040

That being said, every time this legislation refers to a partial lockbox, it also says that if the custodian is concerned about this partial lockbox and feels that the receiving physician or the receiving custodian should have that information for the purposes of quality of care, they can warn the recipient of the information that there's something missing from this health record. That's a bit problematic. What happens in those kinds of circumstances is that the recipient of the record has no idea what has been locked away, starts imagining all sorts of things and becomes concerned.

This scenario of something being locked away actually occurs in practice in this province in the context of police record checks. It's very common for the police to actually record people's HIV status and put it in the police computer called CPIC. It happens every day. When you ask for a police record check from the police station, there's a box on most of the forms that says "other concerns." The purpose of the police check is to ensure that the person who is seeking employment or a position as a volunteer does not in fact have a criminal record and in particular a criminal record associated with children or sexual offences. So you will see these police records for people who have no history of offences whatsoever where that little box is checked. Volunteer agencies and employers who receive those checked boxes want to know what the box is checked for, and they will not place people unless they find out. I know from experience that this withholding but telling that there's something you're withholding is deeply problematic. In practice, it forces disclosure of the very thing you want to keep hidden in order to access the service you're trying to access.

Let's go on to subsection 37(3). Subsection 37(3) is about what I call registry data. It's where somebody calls up the hospital and says, "Is my mom in your hospital?" and they're told, "Yes, she's in room blah, blah, blah, and she's in such and such a condition." That goes on every day in hospitals in Ontario. This section would give patients the right to opt out. The idea is that you can tell the hospital you don't want the hospital to give out this information. In actual fact, we would prefer the opposite: the presumption that the information would not be given out without your consent. The simple truth of the matter is that every patient who gets admitted into hospital goes through an admittance procedure and can answer a very simple question about whether or not they want registry data released. The reason this is important is that with increasing specialization of hospitals, we have identifiable areas in hospitals for HIV-positive patients. We have identifiable psychiatric facilities. So as soon as somebody calls up and says, "Oh, yes, they're on ward B of St Mike's," poof, that person is known to the general public who enquires as being HIV positive. Given the harm that happens to people when that occurs, we think it's reasonable that hospitals should have to pose the question upon admittance; so not an opt-out but an assumption that it won't be disclosed without consent.

Subsection 38(2) is a specific reference to the Health Protection and Promotion Act. It says:

"(2) A health information custodian may disclose personal health information about an individual,

"(a) to the chief medical officer of health ... within the meaning of the Health Protection and Promotion Act if the disclosure is made for a purpose of that act."

In actual fact, the purpose clause in the HPPA, a piece of legislation I deal with every day, is very broad. It says, "The purpose of this act is to provide for the organization and delivery of ... health programs and services, the prevention of the spread of disease and the promotion and protection of the health of the people of Ontario." Anything meets that definition. Anything could be for "the promotion and protection of the health of the people of Ontario." It seems to me that the purpose of clause 38(2)(a) is in actual fact simply to affirm that the Health Protection and Promotion Act, which does have mandatory disclosure clauses in it, is part of an integrated privacy protection legislation. I assume that's the case.

That's not what is happening here. What is happening here is a huge broadening of an ability for a custodian to call up public health and release whatever information they feel, for whatever reason, is in the interests of the public. At the moment, there are very clear mandatory disclosure sections in the HPPA that the health profession is very familiar with. If you want to re-examine the HPPA, personally I think that's a really good idea; that legislation is old. But this is not the way to rewrite the HPPA.

What I would suggest is simply to change the language if the disclosure is made pursuant to that act

rather than for the purpose of the act, because the purpose is really broad.

The big clause for the purposes of the HIV community is actually subsection 39(1). This is what I call the Smith v Jones clause. I'm not sure if you're aware of this. There's a Supreme Court of Canada case called Smith v Jones which was about a psychiatrist releasing solicitor-client-privileged information. The court examined the question of when that was appropriate to be done, when there was a danger or risk. The language the court came up with is not quite the language here. There are a lot of people in the HIV community who would actually say subsection 39(1) shouldn't be there at all, who simply disagree with the principle. There are a lot of people who don't agree with that. It seems to me that this is an effort to mirror Smith v Jones. We have lived comfortably with Smith v Jones for a number of years, so it's OK from my perspective. But I really think you should use the language of Smith v Jones. It already exists; it's already accepted.

What Smith v Jones said was that three factors should be taken into consideration in determining whether public safety outweighs confidentiality.

Basically, is there a clear risk to an identifiable person or groups? One of the things you are missing here is the word "identifiable," a clearly identifiable person or groups. We're not talking about some vague, nebulous, unknown body that may be at risk; we're talking about a clear risk to an identifiable person or body of persons.

Specificity: Is there a risk of serious bodily harm or death? Clearly, the language has been copied.

The third criterion in Smith v Jones is, is the danger imminent? By "imminent" is meant, is there a sense of urgency? Is the danger about to be realized in the near future? There's no reference to the idea of imminence at all in this legislation.

The other thing Smith v Jones said was that if you're going to release what is clearly confidential information as a result of this grave risk of serious bodily harm concern, you should do it in a manner that least impacts upon the privacy rights of the individual about whom you're releasing the information. It seems to me that that makes sense, and that could easily be added into subsection 39(1).

How much time have we got?

The Chair: You have two minutes left.

Ms Carey: OK. Subsection 39(2), as far as I can tell, allows wide-open disclosures to penal institutions. In the context of HIV, that is actually kind of a disaster. There are a lot of people living with HIV who in fact go in and out of the prison system on a regular basis, the reason being because they're involved with illegal drugs; that's how they became infected with HIV. So the population that's HIV-positive in prisons is actually very high.

If you've ever been in a prison, then you know there is no privacy in a prison. If one person knows something in a prison, everybody knows something in a prison. There is no way to keep a secret. If you tell a nurse in a prison somebody is HIV positive, then you essentially tell all the guards and all the other prisoners. As a result, I know prisoners who simply do not seek medication when they go into prison because they do not want their status to be known. They do not want to deal with the stigma and discrimination from other prisoners and from guards that they experience when their status is known. Subsection 39(2) takes away that choice from them.

Let me skip quickly to the access section. As you know, here in Ontario we currently are governed by the common law set out by the Supreme Court of Canada in McInerney and MacDonald. McInerney and MacDonald has worked well for me for years in accessing patient records. This section 49 is not in fact quite what McInerney and MacDonald had in mind.

For example, the section that is particularly of concern is clause 50(1)(e), where the custodian is given the right to deny granting the access if the access could reasonably be expected to result in a risk of serious harm to the treatment or recovery of the individual, so on and so forth. In actual fact, the language in McInerney and MacDonald is not whether it could reasonably be expected but rather, was there a significant likelihood? So it's a higher test in McInerney and MacDonald. You're basically giving custodians more rights to withhold records from patients than they currently have.

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The other problem about this is, I see that the government proposes to repeal section 36 of the Mental Health Act. From our point of view, section 36 of the Mental Health Act is the model we should be copying in this legislation, not getting rid of. Section 36 basically reflects MacInerney and MacDonald. It puts the onus on the custodian to establish why they're denying access to the records. Under section 36 of the Mental Health Act, if a psychiatrist or an institution wishes to deny access to the records, they must make an application to the board to justify doing so. This legislation proposes to take that protection away from patients.

The Chair: You have two minutes left.

Ms Carey: Great. So let me talk about remedies very briefly.

Section 55, if you turn to it, and subsection 55(3) in particular, basically gives absolute discretion to the commissioner to review a complaint or not. So if the commissioner decides not to review your complaint, you have no right to complain. The legislation contains no appeal rights. Most administrative tribunals that have the discretion not to hear a complaint also have a section that says that you have the right to request a review of that decision. There's no such section in here. There's nothing in here about appeal rights to the court, for example. In other words, the commissioner has the absolute discretion to simply do away with complaints. If you have any experience with the record of the Ontario Human Rights Commission, which does away with 99% of all complaints to it without a hearing, then you will recognize that this is a very dangerous thing to allow.

Subsection 55(4) has an entire list of screening procedures. This is also something that is not substantially

similar to PIPEDA. In fact, the federal commissioner doesn't have this ability to screen out complaints and get rid of them without dealing with them without an investigation.

Similarly, in subsection 60(5), if the commissioner decides to not issue an order after a review of your complaint—there's no appeal, there's no right of review—that's unusual for administrative procedures. We would recommend that that kind of thing be put in.

Subsection 63(1), the damages section: This is actually a very good thing. It mirrors PIPEDA to a certain extent. PIPEDA also allows a patient to apply to the court for a damages claim if a breach is found.

Unfortunately, the legislation here refers to "damages for actual harm." This is different from the provincial privacy acts in several of the provinces—BC, Manitoba and Newfoundland come to mind—which specifically say that you apply to a court for damages for breach without proof of actual harm, and there's a reason for this. The idea is that privacy at international law is a human right. The "breach of a human right" should protect the dignitary interest; you shouldn't have to establish actual harm because the public interest is being protected by the remedy for damages.

I'm running out of time; I'm getting the eye.

The Chair: Your time has expired right now. If you have any additional information that you'd like the committee to look over, you could have it sent to the secretary of the standing committee on general government. Tonia could give you the address of where to send it, but I think you already have it. Thank you very much for your presentation.

We haven't got any time for questions.

Mrs Maria Van Bommel (Lambton-Kent-Middlesex): Can we propose a motion to extend the time?

Interjection.

Mr Brownell: I know we're rookies over here.

The Chair: We would require unanimous consent at the present time. The motion was brought about yesterday by the member representing the minister and it would have been for the next presenters. So I'm sorry, unless we have unanimous consent.

Ms Martel: Mr Chair, I don't want you to take this personally, but I'm going to be consistent with what I did yesterday. When the committee first set up its rules, there was a decision made with respect to individual presentations of 15 minutes and groups with respect to 20.

I hope you will send us the rest of your comments because I certainly appreciated what you had to say. I think we've heard many of the suggestions that you made from groups before, particularly representing mental health constituents, and we need to take a look at that. The concerns have been similar in some cases. But I'm going to have to decline consent because I think we have set a rule and we should keep to it.

Ms Carey: Thank you very much.

The Chair: The next group is the Canadian Blood Services. Are they here yet? I don't believe so. We'll take a five-minute recess.

The committee recessed from 1055 to 1104.

CANADIAN BLOOD SERVICES

The Chair: Thank you very much for taking the time to come over and make a presentation to the standing committee on general government. As was agreed yesterday by a motion in Sault Ste Marie, your group will be allowed up to a maximum of one hour for the presentation. If you're taking the whole hour, there won't be any time for a question period, so we'll leave that up to you. You can go ahead. Thank you again for taking the time.

Mr Watson Gale: Thank you for having us.

The Chair: Can we have your name and position, please?

Mr Gale: My name is Watson Gale, vice-president, general counsel and corporate secretary of Canadian Blood Services. On my left is Mr Darren Praznik, the executive director of government relations for Canadian Blood Services, and on my right is Ms Elaine Ashfield, legal counsel with Canadian Blood Services.

Monsieur le Président and members of the committee, thank you very much for having us here today. We very much appreciate the opportunity to speak with you about this matter today.

As I mentioned, my name is Watson Gale, and I am the vice-president and general counsel of Canadian Blood Services. We're obviously here today to speak to you about the application of Bill 31 on the operations of Canadian Blood Services, or CBS, as we like to call ourselves. We are, as you probably all know as well, the national integrated blood operator for Canada, across this country and all provinces and territories, with the exception of the province of Quebec.

I'd like to acknowledge that we've already been in contact with the minister's office with respect to our specific concerns. We are most pleased that the minister's staff arranged for us to meet with them and the department and legal officials who have been working on the wording of this bill, and that we are currently working with them to resolve a number of the issues.

As recently as yesterday we have been discussing some of these matters with them, and I think it is important to note that we at CBS are more concerned about the results of any of these discussions and the application of the bill to us rather than the process or the method by which these results are obtained. I will address that with a little more specificity of it later.

I think it is important also to state that there is a recognition and willingness on the part of the minister's office that these issues do need to be addressed and that the question is, what is the best method of doing that?

In fairness to both the minister and his legislative drafters, Canadian Blood Services is a very unique part of the health care system, and as a consequence, we could not expect that our unique circumstance could be entirely contemplated in the drafting of a complex piece of legislation such as this bill. As such, we are pleased to

have the very speedy and supportive response from the minister's office when we contacted them several weeks ago with our concerns and specific issues.

I would also like to stress at the outset that CBS firmly believes in the importance of safeguarding and protecting the personal health information of our citizens. We understand how important it is to do this. In fact, protecting the privacy of the personal health information of our donors is essential to the operations of a blood system. It is important that our donors, when they make an initial donation and when they continue to make donations in the future, understand that the information they provide to us is kept with the utmost of privacy. For CBS, the protection of the privacy of our donors is essential to the operation of the system.

We would like to tell you a little bit about Canadian Blood Services and what we do. We have found in discussing with the public across this country that very often what we actually do in CBS is not really very well understood. I'm sure it will demonstrate our uniqueness in the health care world and emphasize the issues that we do wish to raise with respect to the effect of certain provisions of Bill 31 as they are currently drafted.

As I mentioned previously, CBS is a unique provider of a health care service in Canada today. We are the only provincially owned and funded provider of health care services that operates on a national integrated basis. As you may know, we do not operate in Quebec; that is in fact operated by an organization known as Héma-Québec. Other than that, we provide all blood supply matters for this country from coast to coast to coast.

Although we are an arm's-length charitable corporation, provincial and territorial governments appoint our board of directors, approve our three-year corporate plan and provide our annual budget. Our operations are regulated by the federal government through Health Canada.

This arrangement was established in 1998 by these 12 provincial and territorial governments, with the support of the federal government, in the wake of the tainted blood scandal of the late 1980s and on the recommendation of the royal commission into the blood system in Canada conducted by Mr Justice Horace Krever. Coincidentally, Mr Justice Krever conducted the commission of inquiry into the health information privacy in Ontario in the early 1980s.

In creating CBS, the Ministers of Health of the day provided it with a mandate to be responsible for a national blood supply system which assures access to a safe, secure and affordable supply of blood, blood products and their alternatives. In addition, CBS was given responsibility for recruiting and managing donors, whole blood and plasma collection, processing, testing and laboratory work, storage and distribution, and inventory management across the country.

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The ministers also gave CBS the responsibility of developing and maintaining a surveillance and monitoring system capable of identifying potential threats to the safety of the blood supply and to take timely and corrective measures. As such, CBS has been mandated by its provincial and territorial owners, including Ontario, to operate a nationally integrated blood system.

So, how does the system work?

Let me first tell you a little about what we do as a blood operator so you'll have an appreciation of the interaction of this legislation with our processes.

By the end of this current fiscal year, we will collect from Canadians in our jurisdictions approximately 850,000 units of whole blood. From this, we anticipate that we will ship to over 800 hospitals in Canada approximately 745,000 units of red blood cells, 400,000 units of platelets, 160,000 units of plasma and 65,000 units of cryoprecipitate and cryosupernatant. These 850,000 units will come from approximately 450,000 active individual donors who on average will donate approximately twice per year. Some of these donors will of course be deferred either temporarily or permanently due to various risk factors, or for whatever reason will not continue to make a regular donation. In fact, we need to recruit approximately 80,000 new donors annually to be able to meet the increasing demands in Canada today. As I am sure you can appreciate, it is a constant effort to maintain this significant pool of donors on which the national blood supply depends.

With respect to Ontario specifically, you may wish to note that of the total CBS production, Ontario hospitals will use approximately 50% of red blood cells, 52% of platelets, 70% of plasma and just over 50% of the cryo products. However, in terms of donations, Ontario generally does not meet its own needs and is a net importer of blood and blood products within the national system. This is demonstrably why a national system is so important to this province.

CBS's work in maintaining and managing these donations from collection to delivery to the hospital door is far more complex than may appear to the general public. Each step, which is regulated by Health Canada, is designed to minimize risk to the health of the eventual recipient of the blood product.

In addition to the tremendous efforts that are required to recruit donors in the first place, the donation process requires that donors answer a long list of questions. We have included in the package of materials that we have provided to you a copy of the Record of Donation. As you can see, a donor is required to answer many questions, including several which involve the most personal of health information. These are mandated by Health Canada and are designed to minimize risk. We are also unable to make changes to this Record of Donation without approval by the regulator. Given the personal nature of the information requested from a prospective donor, it is fundamentally important that we protect the privacy of the donor, and of course we currently do so.

I would also point out that we are required by a Health Canada guideline to maintain this information in our database even if the prospective donor is deferred or chooses not to make a donation. Again, this information

is kept should the person return to make a donation, either in the same or a different jurisdiction. It can assist our medical directors, who may choose to exercise their discretion and defer a donor for a variety of reasons.

Should the donor be cleared to donate, we then take the donation. If any of you have given blood before, you will have noticed that in addition to the blood bag in which the donation is collected, there are also a certain number of vials that are collected at the same time. In order to maintain a closed system and so protect the blood from contamination, it is these vials and samples that proceed for testing while the blood bag itself proceeds to a different lab for processing and manufacturing into the various products we produce. Both of these processes go on simultaneously, sometimes in very different and distant physical locations. For example, all blood testing takes place in one of our three major consolidated regional labs in Halifax, Toronto or Calgary. The manufacturing process, on the other hand, usually takes place in a lab located in the province where the donation was made.

You may wish to note that we can manufacture up to four components from a unit of blood and so benefit four recipients from a single donation.

If any of the tests we conduct produce a positive result, then the sample is sent to the national testing lab in Ottawa for confirmatory testing. In these cases, the donor will be notified by one of our medical directors, who are all licensed physicians across the country. The product, of course, will be recalled or destroyed. If all of the tests are negative, then the test results will be matched with the now manufactured products, which can then be cleared for release into the CBS inventory for shipment to hospitals across Canada where the need may arise.

Although Justice Krever had recommended a vein-to-vein system, this has not been achieved by CBS, and it has not been achieved based on the mandate given to CBS, as we manufacture vein-to-hospital door only. Hospitals that receive product are required to maintain records for the product and transfusions which can be matched to CBS's network through the product unit number if required. Thus, a donation of blood made to CBS anywhere in Canada can be traced to the recipient or recipients and back again if this becomes necessary.

We would also point out that part of our responsibility is to be able to contact a donor should there be an adverse transfusion reaction or a subsequent condition in the recipient that would suggest the donor undergo testing for a possible health condition. This testing is used not only to investigate the source of the adverse condition in the recipient, but also to confirm for the donor that they themselves may have a possible health issue.

I think it is important also to note at this point in time that our donors come to us voluntarily. They do not come to us for any form of therapeutic treatment. They come to make a voluntary donation for the benefit of others who need therapeutic treatment.

With the implementation of the MAK Progesa donor information system over the last year, this system being a brand new, nationally integrated information system, a huge financial contribution has been made by the provinces and territories to implement this. With it, CBS is now able to manage the information flow in this entire process on a nationally integrated basis. This means that a donation collected in Moncton, New Brunswick, manufactured in Saint John, tested in the CBS labs in Halifax and Toronto—the latter being where our West Nile virus lab is—with components utilized in Prince Edward Island, Ontario and British Columbia, can be continuously and instantly tracked by the appropriately authorized CBS official if required. It is this degree of integration in having a truly national blood system, including a national information system, that provides Canadians with the greatest assurance not only of the security of supply, but also of the safest possible blood supply.

You may have noticed already that CBS's operations involve a multitude of integrated facilities and activities across the provinces and territories. These include 14 blood centres, two dedicated plasma collection centres, three regional testing sites, approximately 42 permanent collection sites, a national headquarters, a national testing site, a national donor contact centre, and, annually, approximately 14,000 mobile collection clinics. Consequently, the application of privacy legislation in any given province to a nationally integrated blood operator can be complex and difficult. That is why we are particularly pleased with the interest of the minister's office to accommodate our unique situation and we would hope that the members of this committee would be supportive in making this legislation work for the national blood operator.

I would like now to turn your attention to the five primary areas of concern that we have identified. We have enclosed in your package a summary of these issues and a suggested means of dealing with them. I would like now to take you through CBS's specific concerns. I would like to reiterate that it is the results of these concerns that we are interested in. The method of actually dealing with them by the Legislature is really of lesser importance to us than the actual concrete, practical result at the end of the day.

The first issue to address with you is CBS being a single health information custodian. As we have discussed, CBS operates as a fully integrated national blood system that requires critical donor information to be appropriately available throughout the system. The functions of a blood operator are not housed within single sites or facilities, but are conducted in a multitude of mobile collection clinics, fixed collection sites, blood centres, testing labs and processing labs located both throughout Ontario and throughout Canada. Information or privacy walls between provinces and territories would cripple the ability of CBS to operate on a national basis.

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As CBS currently operates six labs in Ontario that would be defined under the bill as health information custodians, CBS would be covered by this act. The re-

mainder of CBS's operations in Ontario would not meet that definition.

Although Bill 31 does provide a means for the minister to order that these six labs be treated as one health information custodian, the current wording does not provide for the designation to be extended to all CBS operations either in Ontario or on a national basis. The minister can, however, exclude the CBS labs. Consequently, a means does not currently exist to designate CBS's entire operation as a single health information custodian, which would be necessary to respect the integrity of a national blood system.

By example, our MAK Progesa system, which I referred to earlier, is a single database that provides information across the country. To have any lack of availability of that system would create a fundamental lack of ability to operate the system.

We would therefore suggest that this need could be accommodated by an amendment to the following provisions of schedule A: by excluding CBS from subsection 3(1) or by adding a new category of custodian that would include CBS specifically or by reference to a group.

The second matter I'd like to raise with you is the definition of health care and implied consent. The health information collected by CBS is primarily about its donors and is required to reduce or prevent the risk of transfusion-transmitted diseases to the recipient of their donation. We undertake a variety of levels of safety. The first level of safety is this record of donation. By questioning our donors as to risk behaviour, we can identify higher-risk cohorts which then can be excluded from the blood pool. The next major level of safety, of course, is testing. But this primary level of questioning our donors is an essential element to the safety of the blood system.

It is also necessary to be able to appropriately contact the donor should a transfusion-related event or post-transfusion condition in the recipient suggest the donor be tested.

Bill 31, as currently drafted, contains a default requirement for express consent when a custodian is not providing health care as defined. As CBS is currently covered by the bill through the operation of its labs in Ontario, it is necessary that its operations be included in the definition of health care and not subject to the default provision.

As currently drafted, it could be argued that CBS does meet the current definition as we provide a "service or procedure that is done for a health-related purpose" and that this is "carried out or provided to ... treat or maintain an individual's physical condition" or "is carried out" or performed "to prevent disease or injury or to promote health." However, it could also be argued that this provision does not include, in essence, the provision of a biological product such as blood and as such does not therefore include the blood system operator. It is this clarity that we seek.

Should CBS not be found to be included in the current definition, express consent would be required for transfers of health information within CBS. As the system is integrated nationally, all necessary health information across the country would require this express consent from donors.

Currently, CBS has over 1.3 million individuals and their respective donor information in its database and is required by Health Canada guidelines to maintain this information indefinitely for look-back and trace-back purposes. Look back and trace back, by the way, are the processes we go through to identify either a disease in a recipient and to identify the donors who provided product to that recipient or when a donor is identified as having a transmittable disease to identify the recipients of that donor's product. If required to obtain the express consent of these donors to utilize this database, the time required to do so would be significant and could jeopardize the operation of the national blood system.

We would therefore suggest that to ensure clarity the definition of health care be amended to include the functions of a blood system operator or that section 20 be clarified to expressly include these same activities.

The third point to bring to your attention is the issue of withdrawal of consent and the need for the blood operator to maintain information indefinitely.

This is a major concern to CBS as blood operators are regulated by the federal government through Health Canada, which requires that blood operators retain donor information indefinitely. This was also a major issue in the Krever inquiry and is a natural consequence of the recommendations of that inquiry. This requirement is necessary for monitoring the safety of blood and blood products, to screen out donors who have been deferred, to conduct investigations to determine if a recipient has received contaminated blood and to notify a donor to be tested for a possible transfusion-transmitted infection.

The information collected and maintained by a blood operator differs from other health information collected on individuals in that it is not primarily collected for the purpose of treating that individual. Rather, it is required to reduce the risk and protect the health of the recipient of that individual's donation of blood.

If the withdrawal of consent leads to this information having to be placed in a lockbox, the result could include the withdrawal and destruction of product as it could no longer be traceable, failure to identify a previously deferred donor and the inability to trace back a donor for further testing, thereby compromising that donor's health. This would be a major crippling event for the operation of the blood system.

For these reasons, and on the guidance of Health Canada, blood operators maintain a record on all persons who apply to donate, including those who are deferred. This database now operates on a national basis and is a significant part of the blood system safety net.

We would therefore suggest that the bill be amended by adding an additional section that would not permit the withdrawal of consent where the personal health information pertains to a donation or testing for purposes of donation of blood or other body material.

The fourth point is with respect to donor retention and marketing. With the making of a donation of blood, the donor provides CBS with their name, current contact information and blood type. The deferral of a donor, either temporarily or indefinitely, is also contained in the CBS database. This information is used by CBS to contact past donors to ask them to make further blood donations.

The donor's blood type is critical information for CBS in identifying which individuals are needed to meet the current need for specific blood types. This is especially important when certain blood types are in low supply or in high demand or when very rare blood types are involved.

The current provisions of Bill 31 appear to be intended to prevent the use of health information for securing a monetary donation but inadvertently would also prevent the use of this information for the retention and identification of specific donors by blood type without the express consent of the donor.

As you may have already noted, the CBS national donor centre and database servers are located in Ontario, and so this provision has a truly national effect. As there are currently over 1.3 million donors in the CBS database of which over 450,000 are active donors, securing the consent of these donors prior to the planned implementation of this act would be an enormous, if not impossible, task.

The committee may also wish to note that donors are currently protected from unwanted callbacks by federal regulation, which prohibits CBS from attempting to recruit individuals who have indicated their desire to no longer be blood donors.

We would therefore suggest that this provision be refined to ensure the continued ability of the blood operator to retain donors. This can be done, we would suggest, in one of two ways: by regulation to exempt CBS from the provisions of section 32; or by amending section 32 of the act to exempt CBS.

One thing I might also note here is that we have undertaken a major campaign across the country by the name of Roll Up Your Sleeves, Canada! This is our effort to obtain over 160,000 new donors in order to meet the increasing demands for blood and blood products by hospitals in this country. The changing demographics and the increasing demands for hips and knees, cardiac surgery and cancer therapies have created a substantial and increasing demand for our products, which we must be able to recruit and retain donors in order to meet.

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The last piece I'd like to mention to you is with respect to our bone marrow registry. In addition to being a blood operator, CBS also operates the unrelated bone marrow donor registry for all of Canada. The registry maintains a list of potential bone marrow donors, including the necessary health information to be able to be matched with recipients. This registry conducts searches internationally to find a donor when one is not available in Canada. It is also searched by other international registries when they are unable to locate a donor in their own country. Thus, this is not simply a provincial or a national matter, but a truly international health care initiative. Given advances in the science of stem cells and cord blood, these matters eventually will also probably arise.

To facilitate the operation of the registry, CBS will require that health information custodians, as defined in Bill 31, be able to disclose personal health information to Canadian Blood Services as contemplated in clause 38(l)(c) of the bill. We believe that Canadian Blood Services meets the conditions for this requirement as we compile and maintain a registry of personal information that relates to a specific disease or condition, such as the unrelated bone marrow donor registry, and also compiles information regarding the storage or donation of bodily substances.

We are therefore requesting that CBS be granted the necessary status by a regulation and that this regulation be effective at the time of the coming into force of the act to ensure no interruption in the operating ability of our UBMDR activities.

We have much appreciated the opportunity to make our presentation to you today. As a blood operator, our system is built on the confidence of our donors. Protecting the privacy of their personal information is key to maintaining that confidence. As a nationally integrated operation, we would seek your consideration and support in ensuring that Bill 31 will accommodate the unique aspects of operating this national blood system.

We would again like to thank the minister's staff and the minister's department and legal team for their efforts to date in working with us to address these various issues.

Thank you very much. We'd be happy to address any questions that you may have.

The Chair: Thank you very much for the presentation. I think we could take five minutes, each group, to ask questions. I will start with the government side.

Mr Fonseca: Thank you, CBS, for that presentation. It was very thorough.

In regard to all the amendments that you brought up, would a special regulatory provision related to blood collection services address your needs?

Mr Gale: It could very well address our needs. As I've mentioned earlier, the actual method by which our needs are addressed is really of lesser importance to us than actually having the needs addressed. Whether these be addressed by amendment to the bill or by some regulatory power that provides the confidence that these needs will be addressed, I would leave that to the legislative drafters and the legislative procedures as to what is the art of the possible.

Mr Fonseca: I wanted to ask one specific question in regard to when the donor is filling out this form. How much time between the filling out of the form and the giving of blood?

Mr Gale: Minutes.

Mr Fonseca: Have you ever had an instance where the donor decides within those five minutes that, "I don't want to give blood and I want that record destroyed"?

Mr Gale: I'd like to address actually three points that come up in your question.

First of all, this record of donation is filled out every time a donor comes. So it is something that is done at each and every donation.

Secondly, if a donor were to change their mind during the process, there is a process at the very end of the questioning and the information session that allows the donor to decide confidentially, without the presence of a nurse or any other individual, that they will have their unit of blood used or not used. So a confidential bar code is taken by the donor and placed on the record of donation. That bar code, unknown to the nurse or to the collection staff, will dictate that in fact that unit of blood can go ahead for processing or whether it is to be discarded. So notwithstanding the information provided, the donor has an opportunity to not have their blood enter the system.

Mr Fonseca: Prior to that, if the donor decides not to give blood?

Mr Gale: If the donor decides not to give blood, once the donor has applied—effectively shown up at the clinic and started the process—that information is in our system. We are required to keep it and maintain it for it to be available and accessible for the national blood system.

The Chair: Thank you.

Mr Lou Rinaldi (Northumberland): Thanks for the presentation. This gets very interesting as we move along with a different concept. The question I have for you, being of a national scope that your agency provides a service, and knowing that, I believe, there are some other provinces already with legislation in place, are your concerns handled in those provinces, or are we struggling there as well?

Mr Gale: We have a variety of issues, obviously. Being a national organization, we deal with a patchwork of legislation across the country, and it is important for us to comply in every jurisdiction in which we operate. We are able to handle these matters in a number of different ways in other provinces due to the way health care is defined, due to the way custodians are defined, due to the language of the legislation not being applicable to what we do. It varies in each and every jurisdiction. But clearly, in Ontario, because our national contact centre is based here, one of our consolidated testing labs is based here, the servers for our database are based here, it is really of crucial importance in this province.

Mr Rinaldi: Thank you.

Mr Jeff Leal (Peterborough): Do you have a full exchange of information with Héma-Québec, since it's different?

Mr Gale: We don't have full exchange of information with Héma-Québec, but we do work very closely with Héma-Québec to ensure that necessary information on health surveillance is exchanged, that anonymized data may be exchanged, and I say "may." We do have a co-operative relationship. For instance, if we are short of blood or blood products at a certain time, Héma-Québec will assist us, as we will assist Héma-Québec. As a result, the traceability of product must be uniform. Héma-Québec also uses a MAK system, so the information is compatible.

Also, we have a relationship and an understanding with Héma-Québec that in fact we—CBS—actually collect blood in Gatineau on the other side of the river from Ottawa as it is more convenient for CBS to do it with our labs and processes there than it would be for Héma-Québec to do it.

So there is very clearly an exchange of information and a relationship, but it is not a full and complete exchange of information.

Mr Leal: Just one other quick question, Mr Chair. Many communities across Ontario provide their citizens with community awards, and one of the things they recognize is blood donations. If I know that Mr Rinaldi is a blood donor, but I don't know specifically how many donations he's given over a period of time, if I go to you, could you divulge that information to me?

Mr Gale: No, we wouldn't divulge that information to you.

Mr Leal: Thank you.

The Chair: The official opposition side now.

Mr Ouellette: Thank you very much for your presentation. A couple of questions: First of all, on page 5 you mention about the test results, that you contact individuals or a physician would contact individuals if there were any problems. Does that mean if anybody is donating blood and they're not contacted, they're cleared of the diseases you would be checking for?

Mr Gale: Yes. If a donor provided a unit of blood and it went through the testing program and tested negative for the various tests that we do and was released into the system, then there would be no reason to contact the donor for a health difficulty. I think the donor could take it from that that there are no disease markers that show up in their blood.

It may be that a recipient may be the recipient of multiple units. There are many cases in a trauma where there are hundreds of units that are pumped into a recipient. Should that recipient develop a transfusion-transmitted infection of some kind, then we may go back and contact all the donors—it could be a couple of hundred—to identify whether or not the source of that infection was in one of those multitude of donors. There could be a contact of a donor in that context, but if a donor is not contacted by a physician or by their own personal physician through us about the results of their individual test, then in all likelihood it can be taken that their blood is—

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Mr Ouellette: That was a bit of a personal thing, so now I know. But I'd like to know which ones were tested for, because I've never had call back. So that's a good thing. I think that would be a good marketing tool to be able to say you are being tested for these things for your organization.

Some of the other things are: Do you feel that this legislation will cause a training process for your volunteers who work at all the various sites? How onerous would that be on you, if that's what's going to proceed?

Mr Gale: Whenever legislation changes, there is always a training process, an understanding process, that has to be undertaken. I think that our staff across the country are very well versed, as a result of very high standards of regulatory compliance, to deal with changing regulations and changing requirements. I think our staff and our systems are very robust at this point in time. We are very conscious of privacy and always have been. I think we feel that by any standard of privacy we are compliant. The issue for us is not whether our staff are able to undertake the processes. Our issue is whether or not any of the requirements under the bill will consequentially affect our ability to function; not whether our staff will be able to handle them.

Mr Ouellette: Being that you're a national organization, will legislation in Ontario cause you to change processes throughout all the other jurisdictions in Canada where you currently operate, or are you going to have to put something specifically in place just for Ontario?

Mr Gale: We would not put something specifically in place for Ontario. We do regard ourselves as a nationally integrated, single unitary system. As a result, if there is an impact in the province of Ontario, it will be an impact across the country.

Mr Ouellette: So in other jurisdictions that have brought legislation similar to this forward, did you have to implement something at that time?

Mr Gale: We have made some modifications. The way I like to describe it is, rather than trying to adhere to the lowest common denominator, we actually try to adhere to the highest common denominator. We try to incorporate in our processes the requirements of all the provinces and territories to ensure that processes are met in every province, whether it be provincial lab licensing or through our nationally regulated Health Canada-governed activities. We will amend standard operating procedures or centre operating procedures to ensure that we are compliant at all levels. As you can probably gather from that, it is, at times, not an easy task.

Mr John Yakabuski (Renfrew-Nipissing-Pembroke): Thank you for your very informative presentation. As a blood donor for about 30 years myself, I certainly appreciate the changes that have already gone through in the collection system since back in the 70s. Certainly, it would seem, in a nutshell, that your mandate is to ensure the safety of blood and blood products being distributed to recipients throughout the country. With respect to the privacy legislation or some forms of legislation that you've been required to comply with that have been passed by other jurisdictions, how would this particular bill, without amendment, in the short answer, affect you both financially and in your ability to continue to provide the services you are currently providing under the mandate you have from the federal government?

Mr Gale: Let me answer that by example in the extreme. We have a blood donor—the example that I gave in my presentation of a blood donor in New Brunswick or a blood donor somewhere in this province—where the blood is received, information is put into our system and as a result of either a post-donation event or as a result of an adverse reaction in a recipient, it is determined that that person potentially does have an infectious disease—and it could have been, for instance, West Nile virus before there was testing.

If we were subject fully to the application of this current bill, there is the potential that the blood system could be shut down, because we would not be able to transfer information between sites. We would not be able to have a physician in Calgary, first of all, be the recipient of the information from the donation in Ontario and we would not be able, then, to notify back the information to potential other recipients or hospitals across this country as to the units of blood that are affected. We could potentially be prohibited from contacting the donor or the donor's physician. We could potentially be restricted from providing essential public health information to public health officials across the country. Our integrated national donor system would, in the extreme, be shut down. I would suggest to you that would, almost overnight, cripple the health care system across this country, for instance for such things as platelets. Platelets, which are an essential requirement for cancer therapies, have a very short shelf life. They must be used within five to seven days. If we are not able to do that, all of a sudden you're cancelling cancer therapies across this country almost immediately.

Ms Martel: Thank you for your presentation. I heard you say a couple of times that however this gets sorted out, you just want it to be sorted out. Let me ask a question about the legislative changes, because there are a number of pages of proposed changes. Did you do that yourself as legal counsel or did you have some assistance from the ministry staff?

Mr Gale: I'll let Elaine address that.

Ms Elaine Ashfield: Yes, we provided those to legislative counsel at the ministry's office in the course of our discussions. So those were amendments that I have proposed to them.

Mr Gale: These are ideas that we have put on the table. They are not necessarily definitive, they are not final; they are suggestions on our part as to how things might be addressed.

Ms Martel: As I look at the five areas that you're trying to deal with, there are fairly substantial changes to some of the sections; others are a wording here and there that is changed. My concern goes back to the suggestion that we might be able to do this by regulation, because the changes I see here are quite extensive to cover what you want to cover. This leads to a question that was previously raised, but maybe you can be more specific. In the other provinces, do these changes appear in regulation primarily or in the actual bill itself?

Mr Gale: It varies from province to province. In some of the provinces, the actual legislation itself does not

cause us difficulty. Therefore, we don't need to deal with it by regulation. So it varies on a case-by-case basis. In dealing with this, it's very hard to compare the legislation in the various provinces on these very specific issues because of the difference of treatment they have received. As a result, we have tried to focus on this bill itself and, rather than try through our own offices to harmonize provincial legislation across the country, which is a lovely theory, we've really just tried to identify what could be done with this bill itself to allow us to function as a national operator. What we do, then, within our own processes and procedures across the country, is accommodate those processes throughout our system to ensure that it works on an integrated basis.

Ms Martel: I appreciate that. I hope we can do as much as what you want through legislation versus the regulations, because there are quite extensive processes for regulation now. I appreciate that that process is going to be a public one, which I think is very helpful, but there is a lot in regulation already, so it's my hope the ministry can bring forward some amendments that will be to the actual bill itself versus trying to put most of this in the regulation.

Mr Darren Praznik: If I may just add to it, again, our point is that it has to work for us legally—we're not hung up on the method—and we're certainly prepared to work with the drafters and the ministry staff to find ways that do. But it's also important in areas—there is one area we have referenced where we require a regulatory change. I think it was issue 5. That matter can be dealt with by regulation. The point we make is that where a regulation is required, it has to be in place for us on the day the act becomes law. That was why we flagged that, and it is another concern, so that we don't have a gap where we're not in compliance or not able to function.

The Chair: Thank you very much for taking the time. It's been very informative for us. Everything has been registered and will be looked at.

Mr Gale: If I may take the liberty, I never miss the opportunity, whenever I have more than two people in a room, first of all to thank those people who are blood donors and second to encourage those of you who aren't to become blood donors. If for some reason you can't, please bring a friend or a relative. It really is an important part of our system and we truly appreciate the efforts people make on our behalf.

The Chair: This concludes our hearings here in Kingston. Our next stop is in London tomorrow morning. Thank you again.

The committee adjourned at 1150.

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