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Mrs. Joy Smith

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● (1105)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): I call the meeting to order.

Good morning, everybody. I'm very happy today to welcome you to the committee. It's good to see all the members here.

Today we're anxiously waiting to hear your testimony. I'd like to remind you before you start that you will have 10 minutes per organization to make your presentations. We'll hear all the presentations first, and following that we will go into questions for the witnesses.

Pursuant to Standing Order 108(2) and a motion adopted by the committee on March 6, 2006, I'd like to begin this committee meeting. We will begin with Mr. Richard Tremblay, president of the Canadian Organ Donors Association.

[*Translation*]

Mr. Richard Tremblay (President, Canadian Organ Donors Association): Madam Chair, distinguished guests and members of the Standing Committee on Health, I'd like to begin by telling you a little about the Canadian Organ Donors Association, or CODA.

Since its founding in December 1983, CODA has been working in the community to carry out its mission to promote organ and tissue donation and to ensure national recognition of deceased donors, either posthumously or during their lifetime. CODA also arranges for the transportation of medical teams and organs throughout Quebec.

Since its inception in March of 1987, the survival chain has been maintained with the help of numerous volunteer police officers twenty-four hours a day, 365 days a year. Since March of 1987, CODA has transported 7,346 organs or tissue donations, has covered over 1,174,594 kilometres and come to the aid of medical teams in Quebec and elsewhere in Canada and in the United States on over 4,691 occasions. We estimate that since our fleet of vehicles went into service 21 years ago, over 11,985 emergency transportation calls have been answered by our association.

Over the years, we have had occasion to work many times with the families of deceased donors as well as with living donors. We have been able to appreciate just how precious these extraordinary donations really are. As you can see, CODA has developed some expertise in this field since undertaking its mission in December 1983 to promote organ and tissue donations, to pay tribute to donors and to acknowledge the medical assistance provided to ensure the safe transportation of medical teams and donated organs and tissue.

We are appearing before the committee today to tell you about one solution that, we confidently feel, will encourage more Canadians to register as organ and tissue donors. We do not claim to know enough to take a stand on the new regulations governing organ donors. We will leave it up to the medical and scientific experts to make the representations that they feel are relevant to this debate.

Nevertheless, we are concerned about the increase observed in recent years in the number of persons waiting for an organ both in Quebec and elsewhere in Canada. We believe that everything possible must be done to increase the organ and tissue donor pool. You must not lose sight of the fact that a country's success in the area of organ donation is largely a function of its people's confidence in the fairness, quality and safety of the organ transplantation system.

A tremendous gift

> It bears mentioning that [...] to the extent that organ donation combines the grief of the deceased person's family with the hope of persons waiting for a donor, this act can change a person's perception of life and death and help people gain a better understanding of both stages.

As philosopher Jean-Claude Guillebaud observed, organ donation is anything but a benign act. As he goes on to explain, it is one person's tremendous gift to another, the ultimate act of human solidarity, something that clearly goes beyond mere medicine.

In its April 1999 report entitled Organ and Tissue Donation and Transplantation: A Canadian Approach, the House of Commons Standing Committee on Health underscored the crucial role donor families play in the organ donation process and made the following recommendation which, to our way of thinking, is vitally important:

> 10. The Committee agrees that the donors deserve recognition through their families and recommends that:
>
> 10.1 The Governor General of Canada consider offering commemorative medals or plaques in a ceremony to all donor families.

● (1110)

In 1994, CODA officially opened the first memorial garden in North America dedicated to the memory of organ and tissue donors in Canada. Currently, the names of over 2,000 donors are honoured posthumously. For the past 15 years, a memorial ceremony has been held every October at which time family representatives who have consented to allow their loved ones' organs or tissue to be donated receive a donor's medal from Quebec's acting Lieutenant Governor.

For the past several years, the contribution of living donors has also been recognized. This recognition ceremony is conducted with utmost respect for donors who have given of themselves to ensure the health of others. We sincerely belive that this act of public recognition is in line with family needs and ensures their ongoing support for this great and noble cause.

Madam Chair, as I left my office last night, I was going over a letter sent by Québec-Transplant to the mother of a young donor in July 2004. For privacy considerations, I will not disclose the names of the persons involved, but I would like to read the letter to you, because it reflects the tone of my presentation.

> Dear Madam:
>
> Let me begin by extending to you and to the members of your family our deepest condolences on the death of your daughter Isabelle (pseudonym) on June 13, 2004. We would also like to take this opportunity to thank you warmly for consenting to donate her organs.
>
> Through your generosity, several people awaiting transplantation were able to receive a precious gift of a donated organ. From the information we have received to date from the various transplantation centres, the recipients of the liver, pancreas and kidneys are doing very well and have even been discharged from hospital.
>
> On behalf of the recipients, their families and the transplant teams, kindly accept our sincere appreciation. We hope that the organ donation process will help ease your sorrow and bring you the peace you need to deal with the grieving process.
>
> Enclosed is an invitation from the Canadian Organ Donor Association to have your daughter's name inscribed on a memorial to organ donors in Quebec and elsewhere in Canada. This memorial is located in Sherbrooke, Quebec.
>
> To ensure that the name of your daughter Isabelle (pseudonym) is inscribed on the memorial, please send a copy of this letter attesting to the fact that she was an organ donor. Of course, you are under no obligation to do so and there is no charge for having her name inscribed on the memorial.
>
> Once again, thank you for agreeing to donate the gift of life. Yours sincerely,

This letter was written to Isabelle's mother on July 8, 2004. I will conclude my brief presentation by reading to you another letter that our organization received on April 1 last, nearly four years after this young girl's death.

> Good day,
>
> Nearly four years have passed since I experienced the pain of losing my young daughter Isabelle (pseudonym).
>
> Life goes on and I have regained my health. I have worked hard to learn to live again. For me, attending this ceremony is now something that I need to do. I thank God for giving me the chance to make an organ donation. After the dust settles, the importance of organ donation really hits home. Surely that is what my daughter would tell me. I look forward to hearing from you so that I can close the book on the grieving process.
>
> Thank you.
>
> Ms. X, mother of Isabelle (pseudonym).

Madam Chair, on behalf of these families, the donors and the thousands of patients awaiting a transplant, I thank you for welcoming us to the committee.

● (1115)

[*English*]

The Chair: We thank you very much for your presentation. That was very touching, and it certainly allowed the whole committee to hear of the very valuable donation of the gift of life. Thank you, Mr. Tremblay.

I'd like now to hear from the Canadian AIDS Society. We have with us Kim Thomas, director of programs, and Stephen Alexander, programs consultant.

Who would like to begin? Please go ahead, Mr. Alexander.

Mr. Stephen Alexander (Programs Consultant, Canadian AIDS Society): Thank you very much, Madam Chair, and thank you to the standing committee for the invitation for the Canadian AIDS Society to be present at this table and in these discussions.

The Canadian AIDS Society is a national coalition of over 125 community-based AIDS organizations dedicated to strengthening the response to HIV/AIDS across all sectors of society.

While we appreciate the need for ensuring the safety of organs and tissue for donation, we are nonetheless concerned that the guidelines in the safety of human cells, tissues, and organs for transplantation regulations have been changed into a law in which, despite the exceptional distribution clause, gay men and other men who have sex with men have been targeted as a specific population banned from organ donation. It's a law that seems to be based on the assumption that all homosexual and bisexual men are at high risk for HIV, and it's a law that perpetuates homophobic prejudices by equating sexual orientation with sexual behaviour.

This new regulation seems focused on stereotypes of gay men and other men who have sex with men, and it's based on an unproven belief that allowing the gay and MSM population to donate would increase the risk of HIV transmission to transplant recipients.

It's been well established within the field of epidemiology that certain conditions need to be met for HIV transmission to occur. There must be the presence of HIV in bodily fluids, such as blood, semen, vaginal secretions, or breast milk; as well, there has to be a route of infection—for example, specific types of unprotected sexual activity; mother-to-child transmission; sharing of needles or syringes and other paraphernalia used in piercing the skin; or receiving transfusions of infected blood or blood products, transplanted organs, or donated sperm.

The new regulations for organ donation do not define the type of MSM sexual activity that can lead to HIV transmission. Thus, an MSM relationship that is monogamous still can be subject to a ban, while a male having sex with a female can engage in unsafe practices or have safer sex with multiple partners and still be allowed to donate.

Dr. Gary Levy has already told this committee that:

> ...new testing modalities for HIV, including third-generation serology, which measures antibody responses, RNA and DNA PCR, provide transplant practitioners with enhanced tools to screen potential donors and organs. Properly used, they make the transmission of HIV exceedingly unlikely.

Understanding that risk of transmission of HIV by organ donation would occur almost exclusively during what is called the “window period” suggests that with the use of current sensitive enzyme immunosorbent assays and data on HIV incidence among transplant recipients, the risk of HIV transmission through organ transplantation is one in a million.

Canada's organ and tissue donation rate is one of the lowest in western industrialized countries. Donation rates have levelled off at 14.5 donors per million at a time when the need for transplants has increased by 50%.

Identifying high-risk groups of people rather than high-risk activities works to eliminate a lot of people who could be safe donors, and while the argument to target the gay and MSM population continues to base itself on scientific and empirical data, the *HIV and AIDS in Canada Surveillance Report to December 31, 2006* by the Public Health Agency of Canada demonstrates the persistence of trends among women documented in previous surveillance reports. The positive test reports among women continue to increase, and they reached their highest level yet in 2006, at a total of 27.8% of total positive test results. That is a notable increase over 1997, when women represented only 11.1% of total positive test reports.

The PHAC report goes on to state that women account for a substantial proportion of positive test results among young adults and that in 2006 young women between the ages of 15 and 19 represented 63.8% of all positive test reports in this age group. Although MSM accounted for the largest proportion of positive test results in 2006, the heterosexual exposure category continues to account for a significant number and proportion of positive test results.

● (1120)

By using the same logic of incidence and prevalence that excludes the gay male population, the question remains whether there will be more increases in exclusion criteria that will further diminish the already small donor pool.

The Canadian AIDS Society urges the Standing Committee on Health to work toward providing a set of criteria that is equitable to all populations and will allow donor agencies to continue the policy of screening based on individual behavioural risk, rather than a blanket policy of exclusion based on sexual orientation, thus ensuring greater access to organs for transplantation.

Thank you.

The Chair: Ms. Thomas.

Ms. Kim Thomas (Director of Programs, Canadian AIDS Society): Stephen has spoken on behalf of both of us today. I'm just here for questions.

The Chair: Fine.

Thank you so much for your comments, Mr. Alexander.

We'll now go to Mr. McCutcheon.

[*Translation*]

Mr. Laurent McCutcheon (President, Gai Écoute Inc.): Madam Chair, members of the committee, good day and thank you for this opportunity to speak to this question.

I want to start by briefly describing to you the organizations that I represent. I am the President of Gai Écoute, an organization that provides support to homosexuals. Each year we field over 25,000 calls and over one million people visit our websites. I am also the President of Fondation Émergence, a foundation dedicated to educating, fighting and increasing awareness of prejudice. We also spearhead awareness campaigns in conjunction with International Day Against Homophobia.

I believe you are being handed copies of this year's promotional material which proclaims that homosexuality is not a disease.

We understand the need to adopt regulations governing the safety of donated organs. I believe the gay community is in favour of this initiative as well. We learned of this situation in January through the francophone press which had picked up a story originally carried by the English press in December. All of this to say that in my estimation, the gay community was not properly informed about what was happening.

I hope to show through my testimony that Health Canada's decision violates the spirit of the Canadian Charter of Rights and Freedoms which prohibits discrimination, and that Health Canada has the moral obligation to explain its decisions in a way everyone understands. We need to determine whether or not this decision is discriminatory. Let me remind you that under the Charter, decisions of this nature must be well-founded, which is not the case here. Later on, I would like to propose a regulatory scheme.

As for the scientific basis for this decision, I do not have the necessary expertise to take a firm stand one way or another. These scientific regulations go beyond my capabilities. However, I can say that there have been some scientific advances in recent years in the are of virus identification. I am not certain that the regulations properly reflect the progress that has been made in the past few years.

We also have some questions about the five-year exclusion period set out in Annex E. Some groups are excluded for five years, and others, for one year. The regulations refer to a window during which no identification could be given. As I see it, the logical approach would be to exclude people on the basis of the window, not for a period of five years, which seems arbitrary to me. For other groups, the period fixed is one year. We were not given any explanations as to the reason for this decision. We understand the one-year period for certain groups owing to latency.

We also feel that there are inconsistencies in the regulations since these state that no group is excluded, whereas the Annex lists certain excluded groups and leaves it to the health care professionals to decide whether or not to make exceptions.

Getting back to the issue of discrimination, in my view, a government, health care agency or department that makes a discriminatory decision has the moral obligation to justify that decision.

The right to information is a very important right for gay communities. Personally, I feel that our communities are being treated with contempt in this case. Decisions were made without the necessary information being disseminated. We are responsible individuals. Before coming here, I actually underwent some testing so that I could speak knowledgeably about this issue. Even though I have been sexually active for many years, my test results are still negative. In my opinion, Health Canada has a very important obligation to justify its decisions. I personally think that our communities are being treated with contempt in that they were not fully informed about the regulations that were being brought in.

● (1125)

I head up an organization that defends human rights as well as the Fondation Émergence. We conduct information campaigns and we would be willing to work with Health Canada in our communities to help people understand the rationale behind these regulations and what the various risk levels are. You can rest assured that where there are certain risk levels, gay communities are sufficiently responsible to support policies, provided they are properly informed.

Since we are on the subject of risk levels, I feel it is important to emphasize that people will die because they will not have received an organ transplant. Organs for donation are in short supply. People are dying while they wait for a transplant, and yet homosexuals are being excluded as potential donors. The regulations subsequently state that we are not excluded. So then, how should I answer the question on my Quebec health card as to whether I would like to be an organ donor? Should I sign the organ donor card or not? Health Canada officials haven't given me any kind of answer. I have tested negative, but for now, I have withdrawn my consent because I am at an impasse. It comes back to the importance of keeping people informed.

It seems to me that we could do things differently. I propose that a confidential national organ donor registry be established. Homosexuals account for 10% of the population, but only 2% show up in the census. Therefore, 8%, or the majority of the homosexual population, are not officially accounted for in the census. I don't feel this approach is truly adequate.

If I wanted to be a donor, I would have to answer the following question: have you had any high risk sexual relations? The conditions would be explained to me and I would voluntarily register as a donor. The registry could be confidential, but national in scale. When a person dies, a check could be run to see if that person's name is listed in the national organ donor registry. Right now, it is not clear how we should proceed. Do we or do we not sign a card? Families are asked questions in the emergency room. Parents do not know what kind of sexual relations their children have had—at least I don't think they do.

I want to emphasize that people do discriminate against homosexuals and do harbour some prejudices. Our campaigns proclaiming that “Homosexuality is NOT a disease!” have taught us that prejudices still abound. By enacting regulations like these, the Canadian government, and in this case Health Canada, is promoting this type of prejudice against homosexuals. To all intents and purposes, we have been categorized as a danger to society.

We are faced with this situation at a time when we are making a tremendous effort to achieve equality and combat prejudice. It is critically important for Health Canada to implement proper information programs to increase public awareness. This policy only serves to heighten people's prejudice against homosexuals. It does not promote responsible sexual relations, or encourage people to be organ donors at a time when organs are in short supply.

Thank you very much.

● (1130)

[*English*]

The Chair: I thank you very much for you presentation, Mr. McCutcheon.

Now we'll go to Mr. Flear.

Mr. Nigel Flear (President, Egale Canada): My name is Nigel Flear and I'm presenting on behalf of Egale Canada as the president. Thank you for the opportunity to meet with the committee today.

For those of you who don't know, Egale Canada is Canada's only national organization that advances equality and justice for lesbian, gay, bisexual, and trans people and their families across the country. Egale Canada has presented numerous submissions on issues affecting lesbian, gay, bisexual, and trans Canadians before Senate committees and House of Commons committees, and it has held intervenor status for cases heard by the Supreme Court of Canada.

As you know, I am here to discuss the recent Health Canada regulation on organ donation, which is outlined and published in the *Canada Gazette Part II*. It came into effect in December 2007. Egale was not informed of this regulation until earlier this year, when we were notified by the media.

The regulation lists exclusionary criteria for donating organs, one of which is that you are excluded if you are a man who has had sex with another man—MSM—in the preceding five years. They can become donors only if the transplant surgeon signs a form stating they authorize the use of an organ that would normally be excluded. This clearly discriminates against gay men, bisexual men, and other men who have had sex with men, and it targets a specific group in society on the basis of sexual orientation, with no consideration for behaviour.

In his presentation to this committee on Tuesday, March 4, Dr. Gary Levy, the director of the multi-organ transplant program, university health network, University of Toronto, stated:

> This regulation, as written, will not improve organ safety over current practice... the most troublesome exclusionary criterion, the singling out of men who have had sex with men...I personally believe is totally discriminatory.

Egale Canada recommends that Health Canada target high-risk behaviour rather than high-risk groups. Unprotected sex with unknown partners, homosexual or heterosexual, regardless of gender, puts a person at a higher risk of infection. In other countries—Spain, Italy, and Portugal, for example—the donation policy is being refined, measuring against risk behaviour rather than against sexual orientation. Medical experts have already indicated that a new regulation is unenforceable, could worsen existing transplant shortages, and the risk is not in being gay, but in risky sexual behaviour.

On behalf of Egale Canada, I urge you to amend this regulation and make it consistent with the scientific data, rather than treating gay sexual orientation as a risk category.

Thank you for the opportunity to participate in this important discussion.

The Chair: Thank you for your presentation, Mr. Flear.

We'll now go to Mr. Plater.

Mr. John Plater (Chair of the HIV and Hepatitis Committee, Canadian Hemophilia Society): Thank you, Madam Chair and all the members of the committee, for inviting me.

I'm here today on behalf of the Canadian Hemophilia Society. It's an organization that represents people with bleeding orders that has chapters in each province of the country. In many ways, though, I am here to speak from my personal perspective on behalf of the organization. The organization hasn't taken a particular position on this issue yet, but I think my issues are reflective of some of the thinking right now.

Why this issue most matters to me is that I am likely going to need a liver transplant before I die. If I can get one, it may prevent my death. I'm infected with HIV and hepatitis C. I have cirrhosis of the liver. It's not decompensated, so I'm able to manage day to day, and I don't look particularly unhealthy. But I'm certainly aware that my likelihood of requiring a transplant is quite high, so it is incredibly important to me that we make available as many organs as possible.

Of course, I'm also well aware of the importance of the precautionary principle in public health care. The Canadian Hemophilia Society has been devastated over the years by the tainted blood tragedy and has done a lot of thinking about how we, as a society, go about balancing the need for precaution, in terms of infection, versus the need for transplant of these life-giving organs or for transfusion of blood.

Given the history of tainted blood and my own experiences in responding to that, I am also well aware of the importance of informed consent for patients when they are receiving health care—complete, fully informed consent.

There have been some comments today about the science in this matter. You have a lot of information on record on that. I think it really boils down to the precautionary principle and understanding how we deal with the science of probability versus the science of the specific incidence of infectious transmission. That's a debate that has to continue, and it has to be continued in public. It has to be understood by the public. It's an important debate, because at its heart, it is where we get into this issue of discrimination in these situations.

In particular, I want to respond to the suggestion that new testing methods are the answer to our problems. What we've learned through the blood transfusion situation, and are also recognizing in organ transplant, is the importance of both screening and testing together. It's never going to be perfectly safe. Things will always go wrong. Things will slip through the best systems. What we do is put in as many systems as possible to ensure that we minimize the damage done because of the need for transplants and the need for blood. The perfect world would be the world in which we didn't have transplants and we didn't have transfusions because we didn't have accidents and we didn't have disease and we didn't have problems that required them.

I don't want to spend a lot of time today, because I think you also have information on record. Certainly a lot of this is in the background to the development of the regulations, but there are specific, significant differences between blood donation and the system for blood donation and the transplant situation. In particular, there is the volume of blood donation. We don't have a serious shortage, despite there being shortages at different times of the year. With blood transfusion, we don't have the same type of shortage, so obviously larger blanket precautionary approaches are reasonable in that case.

In the organ donor situation—although these regulations obviously involve a lot more than what are really few solid organ donations in this country—the lack of availability of those particular organs means that people, on an individual basis, may be prepared to make different choices. We believe that what is important is the choice of the individual.

The fact that there is the exceptional distribution clause in the regulations gives us some confidence that at the end of the day, the individual patient and the doctor will ultimately decide, based on the best information available to them.

● (1135)

I also want to talk about why I think this particular situation has become so controversial, and then I will end with why I feel, from my reading of what the discussion has been, that we've actually missed what the real controversy is here.

Why is this controversial?

As a lawyer, as I looked over the record of how these regulations were developed, I was actually quite impressed with the process. One difficulty that I saw when the media report came out was that people started to wonder where this all came from. I went to meetings subsequently and people were standing up saying, “I couldn't find these regulations. Where were they? It took me days to track all this information down.”

Frankly, I had found it all in about 20 minutes, and I immediately realized that was because I'd been trained as a lawyer. I went immediately to the regulatory scheme and tracked it that way. Other people looked to the Health Canada website and to where they were used to finding the information. Clearly there was a communications problem at the end of this process and perhaps during the process.

I believe CBC did a lot of the original stories that came out, but it's quite apparent that not much background research had been done. That's tremendously unfortunate, because I think some messages were immediately sent out across the country that simply were not reflective of what the case is here.

As well, clearly this is going to be a living document. These regulations over time are going to change and grow. Science will tell us different and new things. Society will change. Culture will change. There will be changes over time.

Was the reaction to these regulations warranted?

I took a look at the exclusion criteria. As a person with hemophilia who has received a blood product in my life—and it doesn't matter when, or how many years ago, or my present situation—I would be banned from giving an organ donation. I have HIV and I have hepatitis C. I'm on the exclusion list. Also, people who have been bitten by a rabid animal are excluded, but there's already been a controversy, and probably that's not as broad as it should be. If anyone has been exposed to one—and thanks to some years on a sheep farm, I've been exposed to rabid animals over the years, so I'm excluded for that reason.

Am I concerned about this policy? Am I here to fight for it and champion it because I'm worried about infections getting through in that organ that I may get someday down the road? In some ways I'm not as concerned about that. I don't think my reaction to this whole controversy is related to that as much as to the fact that clearly I'm in the most excluded group there is.

Obviously why the MSM population is so concerned about this is the history of discrimination against that population in the country. As I reflected on that, I also asked myself what the closest I'd ever come to feeling that feeling I hear expressed at so many meetings I go to and hear from gay men and lesbian women. The closest I've been to feeling it was probably in high school where as a hemophiliac I was often prevented from taking part in the sort of macho tough-guy sports. I'd often get concerned that people would think I was gay. Thinking about that makes me think a lot about our society and makes me understand the reaction to policies like this. I think we all have a part to play and a part in the blame for that history.

I don't want to be trite, but I think in any other circumstances this would not be an issue. Again, when you look at it from a probability perspective, from a precautionary principle perspective, at the rates of infection in the population, and our ability to narrow on the basis of what are usable criteria, the MSM population is high on that list, as are people who have received blood products in the past, people who used injection drugs that were not prescribed, and people who have tattoos from using shared equipment.

● (1140)

I won't go into it now. I think there is some tinkering to be done on the details of the regulations. But clearly, as I am involved in AIDS and hepatitis C work, consistently we look at the MSM population as a whole, a specific target population for messaging and campaigns to reduce the infection rate in that community along with a lot of those other communities. So that is going to be there for a while.

That's speaks to something, though, another failure for us, and that is our inability to really do a good job working with those communities to reduce the infection levels. We have to ensure that resources are available to do that for them.

The real controversy I wanted to speak to today was the meeting I —

The Chair: Mr. Plater, can I just say that you're over time now, and could you just sum it up so we can go to committee? Thank you.

Mr. John Plater: Yes, it will be very easy.

I sat in a meeting and listened to the process that went into these regulations and recognized that, technically, my organs can be used. My organs can be used. The controversy is that there is no transplant surgeon in this country who will transplant a liver, from anyone, into me as a person who is co-infected with HIV and hepatitis C. You had Dr. Levy here, the head of the largest transplant program in the country, and I realize no one asked him why that's the case. My understanding is that nowhere in the country is this possible. I would have to go to the United States, and I'm just fortunate, as a result of blood compensation, that I might be able to afford that.

The Chair: Thank you, Mr. Plater.

We're now going to go to the questions from the committee. The first round will be seven minutes per person. We'll start with Mr. Thibault.

Hon. Robert Thibault (West Nova, Lib.): *Merci, madame la présidente*, and thank you all for your presentations.

I don't see anybody trying to pull a fast one here. I don't see anything necessarily devious about this whole question, but there's a problem with where we end up. One of the problems with where we end up is that it is true that everybody can donate and everybody typically can receive a donated organ, because of the exceptional distribution clause. Essentially, everybody receiving a transplant now signs a waiver. So you can always say that you can go through that system and anybody can donate, even if you're on the exclusion list, with the proper science of serology, and all of those things that were laid out.

Where I see the problem is that with the regulations now in place, a lot of people are going to feel that they have to remove themselves as donors. I'm a donor; I signed my card as a donor, but when I look at the list, I question whether or not I should have done that. I don't have hemophilia, but I have received cryoprecipitate in the past, in the years that were iffy. I've been fortunate not to have been one of those who developed.... I have a cousin who died; one of my mom's cousins had the same problem I had and received cryoprecipitate during surgery and died of AIDS subsequently.

So I wonder if I shouldn't remove my name from that list. I look at the exclusionary criteria in item e), “persons who have had sex in the preceding 12 months with any persons described in Items a) to d)....” Now, I know a lot of people who couldn't truthfully answer that question, whether they knew if the partners they have had sex with—although I assume they've practised safe sex—have slept with somebody who may have slept with a prostitute or paid for sex in the past five years. I think that is very difficult.

When you look at the probability clause and those questions, I would question the Correctional Service of Canada and the Department of Justice. The Department of Justice would have gone over these criteria, I would presume. To state in the regulations of the Government of Canada that no Canadian can spend 72 hours incarcerated in a Canadian facility without being at huge risk of engaging in risk-factor sex.... If you're automatically excluded for having been incarcerated for 72 hours in Canada, you're telling every man incarcerated over a long weekend for a drunken driving or assault charge, or something, that they will be raped in a facility in Canada. That's the probability the Department of Justice has calculated. I find that a little bit disappointing.

But coming to back what I think is the serious part, people are telling me that they are removing their names from the list of donors, and they would otherwise have been donors.

Dr. Levy said—and I believe he told me this in my office—that the biggest risk for increasing AIDS now is not necessarily from the MSM group, but from young women engaged in anal sex. That's where they're seeing the largest increase now in the AIDS population. But this criterion doesn't remove young women, nor should it. But it removes men who may be in monogamous safe-sex relationships. It automatically removes them, when they should be donors.

I agree with informed consent, as John has pointed out. I should know as a donor and I should know as a recipient...and I think everybody agrees with that. I agree we should take absolute care to use the best science possible and recognize that we will have some risk.

I will perhaps put this question to Mr. Alexander and let the others respond, but having seen the regulations now and knowing that they probably don't meet the test of law—it's questionable whether they will pass the charter of rights, and certainly the delegatory powers.... You can delegate powers, but you can't delegate the delegated power, which is what the Standards Council of Canada has here. We understand that these regulations probably doesn't meet the test of law, but are they reparable? Can we work within these regulations and make them work, so that we don't discourage people from going on the list of donors, and still protect the supply?

● (1145)

Mr. Stephen Alexander: As I said in my presentation, if we were to move to an equitable process, whereby all donations were subject to risk categories as opposed to population categories, then, yes, we can solve this problem. There are other countries in the world that are moving towards this, both with their organ and blood donation processes. Italy has moved to a behavioural risk calculation for eligibility in blood donations, for instance.

So, yes, if we could move to a process whereby all risk is assessed—not orientation or populations—then, yes, we can solve this problem.

● (1150)

[*Translation*]

Hon. Robert Thibault: Mr. McCutcheon, you suggested that the government establish a donor registry. I have a few reservations on that score, in that it would only complicate matters further. Right now, I have signed my Nova Scotia health card and have agreed to be an organ donor Therefore, if I die in an accident, my signature will be duly noted and tests will be done to see if my organs can be used. Hopefully, I can be one of the donors in your registry.

However, will prospective donors not be put off by having to register, to disclose risky behaviours and even possibly to undergo some tests?

Mr. Laurent McCutcheon: On the contrary. if I wanted to be a donor, instead of having to sign the donor portion of my health card—I might not have the card with me when I'm brought to the hospital—I would voluntarily go and have my name added to the registry. This way, instead of asking me if I am a homosexual, I would be asked if I have engaged any risky sexual behaviour. If everything checks out, I would ask to have my name added to the registry. Otherwise, I would not. This way, all people would voluntarily sign up to be donors, with full knowledge of the facts. No one would be the victim of discrimination.

Today, thanks to computer technology, setting up a registry would probably be a less expensive proposition that the gun registry and it just might be more effective. It could be a national registry.

[*English*]

The Chair: Thank you, Mr. McCutcheon.

Monsieur Ménard.

[*Translation*]

Mr. Réal Ménard (Hochelaga, BQ): Thank you.

Madam Chair, I'd like to ask three questions in quick succession. The first is for Mr. Tremblay, the second for Mr. McCutcheon and the third for our friends from the Canadian AIDS Society.

Mr. Tremblay, you have refrained from commenting on the subject-matter of today's meeting. You made an appeal for donors. Please know that your appeal has been heard by members of this committee. Nevertheless, do you believe that Annex E, as currently worded, is discriminatory? To your knowledge, given the new technologies available today, in particular third generation tests known as PCR tests, would accepting donated organs from homosexuals be deemed quite safe?

Mr. McCutcheon, my views are indeed very similar to yours. I do feel that this is clearly discriminatory and merely serves to stigmatize a group. I am familiar with the work that you and your organization have done to end prejudice. I will ask our researchers to confirm my recollection that in 1996 and 1997, Ms. Picard, a member of the Standing Committee on Health at the time, proposed the creation of a national registry. You know that we have some reservations about using the word “national”, but putting that aside, we understand what you are proposing.

Could you confirm by nodding your head that a report was in fact issued, that we are talking about a voluntary, deliberate initiative and that a multitude of checks would be done? Or, should we in fact amend Annex E so that at least risky sexual behaviour is addressed? I value your opinion on this matter.

Finally, I would like my friends from the Canadian AIDS Society to speak to us about how Spain and Portugal have dealt with this issue. Perhaps we could even get some background notes on this from our researchers. It would help us get an idea of how this issue has been handled and perhaps draw some inspiration from this account.

You have the floor, Mr. Tremblay.

Mr. Richard Tremblay: First of all, I want to repeat what I said earlier. The expertise that we have acquired since 1983 is of a technical, not scientific, nature. Our mission has been focused on promoting organ donation and recognizing donors, encouraging them to join the cause and ensuring medical assistance throughout Quebec.

To answer your question, I would just say that we are concerned to see the lists of people waiting for a transplant grow longer, in Quebec as well as elsewhere in Canada. Regarding the new regulations, you can understand that we do not want to take a stand on a decision made by the scientific or medical community. If you're asking me whether or not I am worried, I would say that our association is concerned to see the waiting lists grow longer every year.

● (1155)

Mr. Réal Ménard: Mr. Tremblay, you are not in a position to voice an opinion on third generation tests. You are opting for a more prudent approach, which could perpetuate the discrimination. However, I understand why you are being cautious.

Let's hear from someone who is also prudent, but somewhat more vocal when it comes to discriminatory policies.

Mr. Laurent McCutcheon: The first question pertains to the registry, which would need to be renewed every year. People would have to re-register, since a person's behaviour is subject to change. Therefore, I would make it a requirement that people would have to re-register every year. People could do this at the same time that they file their taxes. There could be all kinds of communication incentives involved. The idea is to make people responsible.

To my way of thinking, the entire population, which would be well-informed, should participate in the organ donation process. There are virtually no good reasons, aside from emotional ones, not to give the gift of life. Personally, if I could donate my liver to the person on my right when I die, I would gladly do so. I think most people would be happy to be a donor, but they have to be given the opportunity to become donors. The technology exists, along with the means.

Your second question had to do with people's behaviour. Annex E of the Standard which excludes people on the basis of their sexual orientation is discriminatory. Perhaps the question could be asked in this Annex if a person has engaged in sexual relations that are considered high risk. Every person, whether male, female, homosexual or heterosexual, would have to answer the same question. That would put an end to discrimination on the basis of sexual orientation. This suggestion is in line with the comments of Mr. Alexander from the Canadian AIDS Society.

It would be an easy step to take, one that would probably be more effective and more respectful of all Canadians. Bringing in more positive measures would be a further incentive for people to register as donors. Right now, homosexuals no longer want to be organ donors. Personally, when I saw the new regulations, I told myself that that was the end of it for me.

[*English*]

The Chair: Thank you, Mr. McCutcheon. I know Monsieur Ménard had one more question.

Mr. Alexander, please.

[*Translation*]

Mr. Stephen Alexander: Unfortunately, I'm not in a position to comment on how things are done in Spain or in Portugal. During the course of our discussions last spring with Canadian Blood Services, we were told that Italy had adopted a system where the focus was on people's sexual behaviour, not on their sexual orientation.

Therefore, as my colleague said, setting up a registry where people would be asked to answer questions about whether or not they had engaged in risky or unprotected sex would be an effective approach, rather than targeting one group in particular.

Mr. Réal Ménard: Madam Chair, can the researcher...

[*English*]

The Chair: We have to go now to....

Pardon me?

Mr. Réal Ménard: A point of order.

[*Translation*]

Can the researcher confirm whether or not this committee did in fact produce a report on a national registry?

[*English*]

Mrs. Nancy Miller Chenier (Committee Researcher): I can speak to the fact that there was an organ and tissue donation report, which one of the witnesses mentioned earlier today. We studied it in 1998, and in 1999 I believe we reported on that. There was a full committee report. It was not specific to an organ registry. That was one of the issues they considered.

[*Translation*]

Mr. Réal Ménard: I thought the committee had recommended...It didn't? All right, we will look into that.

[*English*]

The Chair: We'll check that, for sure.

Ms. Wasylycia-Leis.

Ms. Judy Wasylycia-Leis (Winnipeg North, NDP): Thank you.

I could jump right in on the question of a national registry. I know the committee I was part of did not recommend the registry. It has been an active issue before Parliament. In fact, I've had a bill for many, many years on this very matter.

Perhaps we could have unanimous consent from the committee to advance this bill through all stages, because it would be an important issue, an important way to deal with the issue of an adequate system of organ donations and transplantations in this country.

Mr. Plater raises a very important point here, that in fact we have discrimination built into that system so that people with HIV and hepatitis aren't eligible to receive a donation, even when they need a liver transplant. I think you're saying that; you might want to clarify. It sounds to me as if we need to deal with discrimination at both ends of this system, and that's certainly one way.

Let me give you a chance to answer that question in the context of your questioning of whether or not, if we move away from what the government has proposed and what the Standards Association has proposed, we might not be fulfilling our obligations in terms of the precautionary principle.

We have heard suggestions from many other witnesses that we are missing the boat when it comes to the true risk factors. All we're doing is building discrimination against gay men into the system. I'd like to start with you, and then I've got a few other questions.

● (1200)

Mr. John Plater: Sure. I didn't want to mislead the committee. The restriction on my getting a liver is not codified. It's just the simple fact that no transplant program in this country at the present time will do the transplantations. We've been trying to understand and respond to those reasons. Liver transplant is never a routine practice, but it is becoming available in the United States.

So there's something underlying it, and when it's not a codified thing, I get concerned that it is related to discrimination.

In terms of the changes, again the points are valid in terms of the need for constantly reviewing the regulations and the Standards Association guidelines that underlie them. But it has to be done with a full understanding. There have been some comments here today that I feel aren't completely correct.

There are women who are excluded under the guidelines as they stand. They are involved in certain high-risk activities, and in some of those cases it is tied directly to the activity, for instance, taking money for sex, having sex with an individual who's suspected or known to be infected with HIV, hepatitis C, or HBV. But that being said, you have to understand.... So women are recognized here.

The comment about the increase in the rate of infection in young women is very interesting and very telling about the problems with this discussion. Those rates are percentage increases, which are of serious and grave concern in terms of our ability to get messages through to those people, but the raw numbers are still low compared to the per capita numbers of infection in—

Ms. Judy Wasylycia-Leis: I'm not so sure they're that low. I think others have made the point very effectively that the real growth in the numbers in terms of HIV and AIDS...that the whole demographic is changing rapidly.

A recent study in Manitoba showed that back between 1985 and 1995, the number of women who contracted HIV...or the percentage of new HIV infections was eight. Between 1996 and 2007, one-third of all Manitobans who tested positive for HIV were women. That's almost 500. And one-third of any new infections since 1999 have been contracted by aboriginals.

So the demographics have changed, yet the criteria have not changed. I think what we're trying to do today is figure out a way to be honest with the precautionary principle consistent with scientific facts.

So I want to ask Mr. Alexander and others this question. What are the options? We can recommend that we change the list of exclusionary criteria, or we could go back to the system that existed, which had clear testing and all kinds of measures in place to screen out high-risk behaviour, or we can do what they've done in the United States, where they have some exclusionary criteria, but they're not regulations. In fact, they are not exclusionary; they're just there as guidelines.

What would your advice be in terms of where we should end up as a committee on this matter?

● (1205)

Mr. Stephen Alexander: Going back to what was originally there prior to December, or January of this year, it was a set of guidelines where there were questionnaires and surveys for the donor, if living, or if it was cadaveric, of the family, and it went through all the scientific and empirical testing for disease. If it was found to be tainted and not usable, it went through the exceptional distribution clause and there was physician and recipient informed consent.

I think a measure of those three together would give us something that is safe and equitable.

Ms. Judy Wasylycia-Leis: Mr. McCutcheon, do you want to add your views to what a new system should look like?

[*Translation*]

Mr. Laurent McCutcheon: I believe the focus must be on people's behaviour, not their sexual orientation. The same regulatory framework must apply to both homosexuals and heterosexuals. Risky behaviour is not a function of sexual orientation. That is what we need to focus on.

[*English*]

Ms. Judy Wasylycia-Leis: Okay, and let me ask—

The Chair: Thank you, Ms. Wasylycia-Leis.

Mr. Tilson.

Mr. David Tilson (Dufferin—Caledon, CPC): Thank you very much, Madam Chair.

I'd like to enter into some dialogue with Mr. Alexander on the topic of the comment that these regulations may have homophobic prejudice. I can't remember who mentioned that, but I believe it was you who mentioned that you'd had some communication with the Canadian Blood Services.

I knew someone in my riding who died a number of years ago and it was eventually determined that he had AIDS. He acquired this through receiving a blood transfusion. Someone had donated blood and he'd received it. Of course, shortly after that time there was this tainted blood scandal. It was awful. It was quite a few years ago. It has to be 20 or 25 years ago. It was a terrible thing. People died and it was awful. It was quite a while ago.

After that time, when you went to give blood it was made much more difficult. I believe there are provincial regulations and there are national regulations. I just went on the website and got part of the questionnaire that you have to sign, from the Canadian Blood Services.

And you read some of the questions that are asked. It's very similar to the regulations. Just read some of them. Do you have AIDS? Have you ever had a positive test for HIV or AIDS? Male donors: have you had sex with a man even one time since 1977? Female donors: in the last 12 months have you had sex with a man who has had sex even one time since 1977 with another man?

There are a whole bunch of questions about drugs and a whole bunch of questions about other diseases. In the past six months have you had sex with someone whose sexual background you don't know? Were you born or have you lived in Africa since 1977? Those are rather controversial questions that you have to sign. Unless you sign them, you can't give blood. And then there's something else.

I think it was you who said you'd had some discussions with the Canadian Blood Services. My question is this. Is what's going on with this—when you give blood—any different from what goes on with organ donations? Is the philosophy with trying to protect the recipient because of these questions and these statements any different from trying to protect the recipient with respect to organ donations?

● (1210)

Mr. Stephen Alexander: The philosophy of ensuring a safe blood supply and a safe organ supply remains the same throughout. The philosophy of using the gay population and targeting them as vectors of disease, however, drastically needs to change.

In a day and age where the gay fight has come from being viewed as a mental disorder to where we now are supposedly equal people in society can be vastly undermined by such targeted exposure and criteria that really put a negative slant on being gay.

You will notice that Canadian Blood Services in 2005 did a revamp of their criteria and what were criteria that would exclude five to ten years got changed. Gay men are still excluded for life from ever giving blood.

The whole point is that not all gay men take part in risk activity. There are heterosexual people who take part in risk activity. We don't want to say it, but anal sex is one of them. And if you're going on a basis of risk behaviour, then you have to include all risk behaviour in all categories of people and not just exclude it to gay men.

Safety is paramount, yes. We really need to find a way where safety can be had without the prejudice against gay men.

Mr. David Tilson: Someone over here made the statement that there are new screening tests or processes. I think it was you, Mr. Plater, or one of you. It was also acknowledged—at least I got the impression, from the new screening, the new testing—that science has improved over the years, but it's still not perfect. So if one acknowledges that issue, then one asks this question, and I'm going to ask it to all of you: is Health Canada's primary duty or responsibility to the recipient or to the donor? Anybody?

[*Translation*]

Mr. Laurent McCutcheon: Health Canada has a duty to all Canadians. If measures are taken to deprive recipients...We know that there is a shortage of organs. Any policy must therefore take into account the overall situation.

I understand that the current policy is based on concerns for safety. We are all aware of past problems with blood donations. The emphasis has shifted to policies where safety is the primary consideration. In the process, if recipients are not receiving organs, then I think the policy and the regulations need to be revisited. All facets of the problem must be considered.

If I were a public decision-maker, it would be in my best interest to make a decision that would not leave me open to possible legal action. We saw what happened in the past, after the Krever inquiry. I would want to opt for very safe policies too. However, as a result of this approach, the list of people waiting for a transplant is growing and the shortage of organs available continues to be a problem. Public decision-makers are protected from prosecution. While they have carried out their duty to protect the public, they have failed to ensure that people awaiting a transplant receive the organs they need. The waiting list is long, but few organs are available.

[*English*]

The Chair: Mr. McCutcheon, I'm sorry to interrupt you, but we have gone over time. I thank you for your comments.

We're now going into the second round. It's five minutes per person, and we'll begin with Ms. Kadis.

Mrs. Susan Kadis (Thornhill, Lib.): Thank you, Madam Chair.

Welcome to all our...[*Technical difficulty—Editor*]

In your view—all of our witnesses—is there adequate scientific evidence to justify any of the exclusion criteria? I know we've been focusing on one particular one, but we have an array there that is set out in the standard. Do you feel the case has been made and that there is a scientific basis for the new regulations, the new exclusion?

● (1215)

Mr. John Plater: Yes, there is, in my opinion. There's fine tuning that needs to be done. Some parts of it are not as clear-cut as others.

One of the particular issues is the amount of time from the behaviour to the date of the proposed transplant, but obviously my position is to err on the side of caution and inform the recipient of the best knowledge available, so that they can make the decision about receipt. But essentially, yes.

It gives me a quick opportunity to respond to the point about the increase in women. Of course, there's an increase in women, a very concerning increase in women. How many of those women are not women who have used intravenous drugs or had sex with someone infected with HIV, hep C, or hep B, or are at serious risk of that? The numbers again go lower. If the day comes when the prevalence of women as a population who have sex with men or with women increases to a significant rate, then there may be room to add them to the list.

I always envisioned a country where we were working towards reducing the infection rates in all of these populations and getting people to understand the importance of safety in sexual encounters, in drug-use encounters, etc., so that we could lift the ban on everybody. Unfortunately, the stats tell us we're not headed that way. We're actually in a reverse trend, where we're going to be adding more people to these lists and not removing them.

Mrs. Susan Kadis: Mr. McCutcheon.

[*Translation*]

Mr. Laurent McCutcheon: We continue to come back to the same point. I believe that we can justify excluding some people based on the level of risk. However, do we need to target a particular group of people, or persons of a certain sexual orientation, or should the focus be on behaviours? I see no problem with listing in the Annex behaviours that are deemed risky, with stating that if a person has engaged in a certain type of behaviour for a certain number of years...However, I cannot accept the regulations as they now stand. Currently, if you are a man who has had sexual relations with another man, even though you used proper protection, as you were taught to...Health Canada does educate people on proper prevention and protection measures. All of Health Canada's policies must be consistent. I would be fully in favour of drawing up a list of exclusions based on behaviours.

[*English*]

Mrs. Susan Kadis: I would like to hear it from all witnesses.

Mr. Alexander, are the exclusions we're talking about justified, in your opinion, on a scientific basis?

Mr. Stephen Alexander: There are particular ways in which HIV is transmitted, and they are all risk- or activity-oriented. It is not person-oriented. All the science in the world shows that. That science should be the basis on which we base some of our judgments.

Mrs. Susan Kadis: Can you address the issue of consultation? It appears to me, as we've again heard reference to today, that because there wasn't adequate, in your opinion, consultation, we're now almost in a process of having to go back, I guess, to the original decision and rethink it. Why weren't groups such as yours, others that are affected, and stakeholders consulted? What would seem to be the reason why they wouldn't consult with you?

The Chair: Time is just about up. You have about 30 seconds to do the best you can, Mr. Alexander.

Mr. Stephen Alexander: I don't know. There were many groups that were not consulted. It could have been the process. It could have been the difficulty in navigating through systems to get to the documentation you needed to know that this was coming about. It could have been knowing that to consult would end up with these discussions and therefore slow down the process that was wanting to be done more quickly.

● (1220)

The Chair: Thank you, Mr. Alexander.

We'll go to Mrs. Davidson.

Mrs. Susan Kadis: A point of order, Madam Chair. Perhaps we can discuss this after the session, but can we have another session with the health department on this? I think it's absolutely warranted.

The Chair: We'll discuss that later. Let's hear our witnesses first.

Go ahead, Mrs. Davidson.

Mrs. Patricia Davidson (Sarnia—Lambton, CPC): Thanks very much to our witnesses for being here this morning. Certainly it's interesting to hear the discussion that's taking place.

We've been hearing from everybody that informed consent and the precautionary principle are things everybody believes in and that we need to have safety of the public as the utmost concern. But there are other issues that each of you have brought to us today.

Mr. McCutcheon, I wanted to ask you a question. You said, I think, that if the criteria were changed, for example, to high-risk sex from the specific, as in annex E, you could support that. I don't know if you actually said you could support it. That would be perhaps a way to go.

Who would define, then, this high-risk sex, and where would that definition be? Would that be part of the annex as well? Would it be Health Canada that defines that? I would like you to answer that question.

Then I have a question for Mr. Plater. You talked about things that needed to be done, and I think you said that some minor tinkering needs to be done with the regulations as a whole. When Mr. McCutcheon is done, could you comment on that, please?

[*Translation*]

Mr. Laurent McCutcheon: I am not a scientist, but I do believe Health Canada knows what type of behaviour is considered risky. AIDS awareness groups already know about risky behaviours as well. It wouldn't require any extensive research. We know how this virus is transmitted. Therefore, we must focus on transmission methods and draw up a questionnaire. That is what I would suggest. I don't have a problem with someone asking me if I have had anal intercourse recently with another man, but when we are told that because we are homosexuals, we do not have the right to donate our organs, then to my mind, this is discrimination within the meaning of the Canadian Charter of Rights and Freedoms.

[*English*]

Mrs. Patricia Davidson: Thank you.

Mr. John Plater: In terms of the tinkering, one of the issues that's been raised is with regard to moving to a risk assessment of the behaviour. One of the concerns, particularly in organ donation—and let's use liver as an example—is that you're usually getting consent from the family of the deceased.

The understanding is, from the work that was done and from talking to people who do this, that it is very difficult to get good information about risk behaviour in those circumstances. It's often late at night, following a tragic accident, and you're asking family members. Sometimes they're the partner of the person; often they're not the partner of the person. You're asking that person, “Did your loved one who just died have anal sex? Did your loved one who just died use sex toys and share blood during sex?” It's difficult to get the answer you want there. That's why you blow it up to a population level, narrowing the population as much as possible.

An example of the tinkering would be, for instance, on the tattoo guideline. The tattoo guideline asks whether you have gotten a tattoo for which equipment was shared. My view would be that's just as difficult to determine from a family member's point of view as the type of sex a person has. If the person has had a tattoo, that should be listed, and that information should be given to the recipient. That would be the end of the discussion on that one. That is the kind of tinkering that I think needs to be looked at.

There was a comment raised about the prison system. I would actually suggest you all spend some time looking at the health status of the inmates in our prisons and our jails across this country, and you'll learn that it is exceptionally dismal.

I would say the tinkering is not in the limiting amount of time; it's the fact that there's a 12-month exclusion there as opposed to the longer five-year exclusion. That's the kind of tinkering that I think is going to need to be happening.

I've been in presentations by the ministry, and my understanding is they fully view that this will be an ongoing process and it will be modified. One of the reasons they went with the approach of using the standards organization and the regulatory process is that it would allow that to happen much more quickly. Remember, it has taken an 11-year process to get here.

Eleven years ago this was called for as necessary to regulate what was just an ad hoc guideline approach across the country—I probably shouldn't say “ad hoc”—which we recognize doesn't always work. It works for the people with laudable intentions. It doesn't work for the people who are cutting corners on a day-to-day basis.

● (1225)

The Chair: Thank you very much, Mr. Plater.

Madame Gagnon.

[*Translation*]

Ms. Christiane Gagnon (Québec, BQ): Thank you for joining us today. It is important to us that the gay and lesbian community be well represented so that it has an opportunity to convey to us its opinion on the new regulations and standard.

I would like to come back to a point that has been debated to some degree. Mr. McCutcheon, you stated earlier that these regulations violate the Charter. When I look closely at grounds for discrimination under the Charter, I see that in fact...

In the event the regulations and the standard are not amended, or that the committee fails to make the government see the error of its ways, what recourse do you intend to take? Do you intend to take legal action of some kind? If you put the regulations to the Charter test, what do you intend to do to take this case to the next level?

Mr. Laurent McCutcheon: Right now, I have to tell you that personally, I have not considered a legal challenge, particularly since the Court Challenges Program has been abolished. No longer can we opt for this legal course of action. What we can do, however, is fight to have this decision changed.

On the one hand, we have the law, and on the other hand, we have common sense. I think that common sense dictates that the danger here lies in people's behaviour. The risk is associated with the behaviour. If we want to prevent infection, we must focus on behaviours.That seems quite clear to me. We must focus on behaviours and ensure that overall policies are consistent.

I think everyone, including myself, agrees that regulations are needed for safety reasons. While recipients must not be exposed to risk, they must not be left to die either. Right now, many people are dying because they did not receive an organ. People don't seem to think this is important enough. Personally, I have a great deal of empathy for people in this situation. People are dying because organs are in short supply and all the while, there are people out there who want to be donor, but are excluded. Common sense must prevail. A person on death's door might be willing to take the chance, if the odds of his being infected are one in a thousand.

Ms. Christiane Gagnon: Mr. Flear, you heard the answer to the question I just raised. How do you feel about possible legal action or a claim based on the Charter's prohibition on discrimination on the grounds of sexual orientation?

[*English*]

Mr. Nigel Flear: We obviously prefer to dialogue in whatever manner is the most productive. So in this case, we would have preferred to have been involved in the discussion when Health Canada was drafting the policy. We made this criticism at other times. For instance, Statistics Canada produced a census questionnaire that also was fairly unfavourable toward the gay population. We've had opportunities to dialogue in the past, and we obviously would prefer to dialogue before we came to a committee to have to discuss a policy that isn't particularly favourable.

As far as charter challenges go, typically Egale Canada will look at it on a case-by-case basis. As was mentioned, the court challenges program very much limits our ability to look at that. It may not be a charter case, but we'll certainly look at any case that involves the LGBT population that we think is unjust or discriminatory.

● (1230)

Mr. Stephen Alexander: Like our colleagues from Egale, we prefer to be present at the table and to dialogue on these issues. We also are the organizations that have the transmission guidelines. We have the empirical and scientific data about HIV that we can share. We have the lived experiences of folk that we can share. So our position would be to dialogue.

The Chair: You have a very short time, about 30 seconds.

[*Translation*]

Ms. Christiane Gagnon: Is the idea of creating a registry something new? I know that the committee may have considered it before. Are people generally in favour of this initiative? Do you have the support of some associations? Have you looked into whether the public is interested in this proposal?

Mr. Laurent McCutcheon: Everyone is looking for solutions. To my way of thinking, this is a practical solution and the few people I've spoken to were in favour of the idea. We now have access to technology that was not around when the tainted blood problems occurred. It would have been difficult back then to set up a national computerized registry. Today, virtually everyone has Internet access. It would be a simple matter to update the data every year. People would register voluntarily. There would be no need to have parents answer questions when someone is brought unconscious in the emergency room. I think this approach would be safer and at the same time, it would promote awareness of the need for donors.

Naturally, I am an advocate of gay rights, but I am saddened to see that people may be dying because there are no organs available, when there are people out there who want to be donors. That's just defies comprehension. While it may not resolve every single problem, a registry would increase the number of donors and help save a few lives over the course of a year and for that, it is worth the effort.

[*English*]

The Chair: Thank you, Mr. McCutcheon. I'm going to have to interrupt you.

Mr. Brown.

Mr. Patrick Brown (Barrie, CPC): Thank you, Ms. Smith. I appreciate all the comments by the witnesses today.

Surely this issue has been around for a long time. It has continued successfully now under three prime ministers and eight ministers of health. It is good that we continue to try to understand it better and protect the standards we have.

I heard a comment about consultation, I think by Mr. Flear. I wanted to provide some comment and see what your thoughts are on that.

The Library of Parliament provided members of this committee with some background information. One thing that struck me when you mentioned consultation was that in the Library of Parliament report it said that in December 2007, when the new regulations came into force, it seemed that some stakeholders were surprised. It also mentioned that on these new regulations there was heavy consultation. Health Canada received requests for clarification from 15 organizations, and recommendations were given from 32 organizations in December 2005, based on the pre-publication of part I of the *Canada Gazette*.

I would also like to add that there was a letter that members of this committee were sent by the Canadian Standards Association, which I found interesting. What they raised was that they were surprised when this was raised too, about the lack of consultation, because individuals who said that—it was their suggestion—may have missed the pretty intensive consultation and opportunities that existed for everyone to have a voice in this.

Health Canada conducted comprehensive stakeholder consultations during the standards development process, sending out over 900 notices to stakeholders, indicating that the CSA standards were available for comment.

To seek input and comment, the draft standards were sent to the president and members of the Canadian Society of Transplantation in 2002. Additionally, there were regular presentations by Health Canada officials to the society and to other transplant associations.

It was certainly interesting to see how much consultation happened and to hear that some felt there wasn't enough.

I guess my comment is that the 900 notices that were sent out and the 32 organizations that became actively involved in having a voice—how could that have been broadened? In the future, do you have any suggestions for how we can have an even more enhanced consultation that reaches beyond 900 people?

Mr. Nigel Flear: Obviously the consultations would be based on health organizations. Egale, for instance, isn't a health organization. We do represent a population that gets discriminated against and is referenced in the risk criteria. We do dialogue also with Canadian Blood Services on the blood issue.

On the fact that we weren't included in that, a number of the people today have said they found out through the media that they weren't included in the 900, and that is obviously an oversight.

We hope in the future, if we continue to discuss this, that we would be informed if there any more mailings.

● (1235)

Mr. Patrick Brown: I'm reading that this was in December 2005; I guess that commenced during the tenure of the previous government. In the list that was compiled of 900 organizations that were consulted, was there any attempt by your organization to suggest that they should also be included on that list that was developed by Health Canada?

Mr. Nigel Flear: We weren't aware of it specifically. We are a very small organization. We have a very small staff. In our ability to research all the options out there, we do depend on feedback from our members and from the media to learn about things.

Mr. Patrick Brown: Okay. Are there any other comments in general about the consultation? Were your organizations consulted, or was it just the one organization that was missed?

Mr. Stephen Alexander: It would be interesting to see who the 900 were that were consulted. The Canadian AIDS Society was not, nor any of our member agencies, or it would have been brought to our attention.

Surprisingly enough, Dr. Levy wasn't consulted or didn't know, according to his testimony.

It would be interesting to see who they were.

Mr. Patrick Brown: Yes, and as I said, because this has gone over such a long time, it would be interesting to find out from some of our colleagues...with the previous prime ministers and health ministers, that this was embarked upon.

I want to delve into and touch upon whether any of your organizations have looked at the standards in different countries. How do the Canadian regulations compare to some of our colleague nations around the world? Have you done any research?

The Chair: Time has passed, so perhaps you could just briefly answer Mr. Brown's question.

Who would like to take that?

Mr. Plater.

Mr. John Plater: I know from the information I've been privy to through some presentations that there was consideration of the American situation. One of the issues is that there's some—it's very limited, but there's some—suggestion of some cross-border transport of organs, in particular, and I know there's more around the tissue area, but there was an attempt to have some lining up with that. Other than that, I don't know.

In terms of your first point, though, I think it's a very good one. NGO organizations have a difficult time keeping on top of all the possible opportunities to give advice. At the same time, I recognize that it's hard on the inside to recognize, across a large country like this, everybody you should ask for input. This was a process where input was invited, but if you're not aware of the invitation because you're not able to regularly monitor these systems, it's hard to get the information back and forth, even over an 11-year process.

The Chair: Thank you, Mr. Plater.

Ms. Wasylycia-Leis.

Ms. Judy Wasylycia-Leis: Let me add to what Patrick has just said. Not only is it likely that if you weren't on the regular list of people to be consulted about organs, you wouldn't have received the notice, but also, based on our information, there was no reference to the exclusionary criteria in a specific sense, so people wouldn't even know that this list actually said, “Exclude men who have had sex with men in the preceding five years.”

We know the standard reference in the regulations was not attached to the gazetted regulations. We know it was not posted with the electronic version of the regulations, and it's not easily accessible online. So who the heck would have known? And you didn't receive any direct notice. It tells me that we need to go back to the drawing board and start again and make sure that everybody is consulted properly.

I want to ask Nigel and others a question around the contradictions of this government. On the one hand, it appears to be ready to be real tough in excluding men who have had sex with men in the preceding five years from ever donating organs. These are men who have no evidence of high-risk behaviour; they could have monogamous relationships with one man in a longstanding marriage, yet they're excluded. But an organization like Kali Shiva, in Winnipeg, which helps deal with high-risk populations in terms of HIV and AIDS—I've read the Winnipeg statistics, and we're dealing with a high incidence among women and aboriginals and sex trade workers, and so on—has been cut back in its funding by the federal government because it does too much work on harm reduction. Maybe you can give us some enlightenment on that point.

Also, let me raise the issue of the precautionary principle, which seems to be the *modus operandi* of the government on this issue, even though there are no risk factors associated with gay men necessarily. They don't want to talk about all the other high-risk areas, such as multiple sex partners, unprotected sex, use of a sex trade worker, and so on, but they'll single out men who might have a monogamous relationship. How do you justify use of the precautionary principle around that when in fact when it comes to things like bisphenol A, which is a hormone disrupter that could cause breast and prostate cancer, the government says, “Well, we're going to wait and see if there's any harm done,” even though the science is in?

Maybe some of you could explain some of those issues and say whether or not you agree, first, that we need to amend the regulation consistent with scientific facts, as Dr. Levy said; secondly, that we need to establish a strong national organ transplantation agency, with a registry; and thirdly, that we need to consult broadly with experts before instituting changes through legislation.

Jump in.

● (1240)

The Chair: Quickly, because there are two minutes left.

Mr. Nigel Flear: Certainly we would hope they would use science to decide what are the most appropriate risk factors to assess. It doesn't matter what government is in power.

We certainly would be interested in participating in any amendment that occurs with the procedure.

Ms. Kim Thomas: I just want to respond to the point you made around organizations such as Kali Shiva, which has seen funding cuts. I think that is probably an issue that the health committee could explore separately. But certainly the discussion of harm reduction, in terms of transplant and transmission, is one the Canadian AIDS Society has a lot of experience with, and we would be very interested in exploring that further with you and sharing more information if you need it.

Mr. John Plater: I would add this: don't go back to the drawing board; take the very good work that's been done and work with it. Your idea about adding people who pay money for sex is definitely one of those tweaks that needs to be in place. I'm always looking for more resources to prevent the spread of any of these infectious diseases.

The Chair: We're close to the time. Unless you have any other comments, you've got about 40 seconds. No?

Mr. Fletcher.

Mr. Steven Fletcher (Charleswood—St. James—Assiniboia, CPC): Thank you, Madam Chair, and I'd like to thank the witnesses for coming today.

I think it was Mr. Tremblay who explained what they do in Quebec for families who donate members' organs, and I think that is an excellent suggestion. I hope we can include that in our final report as something that all provinces should do.

I have met Mr. Plater before because we dealt very closely in getting compensation for hepatitis C victims who received tainted blood outside 1986 and 1990. When I was health critic, the stories about how those people were denied were just terrible. I don't want to get too partisan, but it was the scandal of scandals. I think we want to avoid that type of situation. I think everyone wants what's best for the recipients, because they're the ones who need help the most.

I want to correct a few things that have been said. Mr. Alexander, the Canadian AIDS Society was definitely consulted by Health Canada, and we can provide you with all the specifics afterwards if you wish, but your organization was definitely consulted.

A fundamental issue here deals with.... There is an exemption available for organ donations. Men who've had sex with men are not banned from providing their organs. I want to read what has been said by Health Canada officials in a previous meeting:

> ...Health Canada does not prevent anyone from being considered as an organ donor. Despite the identification of risk factors based on science, an exceptional distributional provision in the regulations allows transplant of an organ from a donor considered to be at higher risk, provided that the transplant physician judges it to be in the patient's best interest and the recipient gives their informed consent.

We're doing the best we can, and the regulations do allow flexibility in exceptional situations. So it seems the balance has been established.

I want to get your comments on the exemption, and maybe a reaction is not necessary.

I would also point out that some concern is being expressed that the exclusion criteria of the cells, tissues, and organs regulations are unconstitutional. In 2007 the issue of consultation validity was of men having sex with men. The screening criteria was considered by the Ontario Court of Appeal in the context of the charter challenge to the semen regulations. The Court of Appeal found the MSM exclusions were not substantively discriminatory and the court emphasized that the health-based rationale for the exclusion criteria is a logical one.

● (1245)

Given that the exclusion criteria are less stringent for CTOs, and given the prevalence of infectious disease transmission, and given that the CTO regulations contain a mechanism that enables the use of CTOs even if they're initially excluded, how could it reasonably be concluded that one exclusion criterion is unconstitutional?

The Chair: Mr. Fletcher, could I interrupt you for a moment? Your time is running out.

Mr. Steven Fletcher: Yes. Those are all my questions.

The Chair: There's no time for answers now. I'm sorry.

Mr. Temelkovski, it's time for you.

Mr. Lui Temelkovski (Oak Ridges—Markham, Lib.): Thank you very much.

I was hoping Steven would sing a song in the meantime there.

Thanks to the presenters. I have three questions.

Number one, could Mr. Tremblay and Mr. McCutcheon tell us about the Italian program and how they moved from population- to risk-based behaviours?

The second question is about court challenges. Mr. McCutcheon mentioned that he'd used the court challenges program before. Nigel also mentioned that. Maybe you can tell us a little bit more about the court challenges program and your inability to use it, or about that program not being available.

Number three, if I read Stephen Alexander's and Kim's behaviour correctly when Steven Fletcher was noting that they had been consulted, I read that they had not. Maybe they could tell us if had been or had not been, and Mr. Fletcher can table the report that says they met and what they met about.

Thank you.

The Chair: Who wanted to start? Mr. Tremblay.

[*Translation*]

Mr. Richard Tremblay: Would the member be so kind as to repeat his question. I didn't understand it.

[*English*]

Mr. Lui Temelkovski: It is in regard to the Italian program of moving from population-based to risk-based behaviours.

Was it Mr. Alexander? Yes. I'm sorry.

● (1250)

The Chair: Mr. Alexander.

Mr. Stephen Alexander: I don't know the exact process they went through. I just know they have, especially with blood donation, moved from a population criterion to a risk-behaviour criterion. There has been documentation also on solid organ donation in that area.

Mr. Lui Temelkovski: Mr. McCutcheon.

[*Translation*]

Mr. Laurent McCutcheon: I made a passing reference to the Court Challenges Program because I was asked what our organization intended to do. Community groups like mine do not have the resources to undertake court challenges. In the past, the program allowed groups to take their fight to court, but it has since been abolished.

With your permission, at this time I would like to respond to a comment from Mr. Fletcher about the Annex and the regulations. In my opinion, the criteria are properly set out in the regulations. Homosexuals are permitted to make organ donations. The problem lies with the Annex which, as I see it, is not consistent with the regulations. The Annex refers to exclusion criteria. Is sexual orientation a criterion for excluding someone? I even feel that the title of the Annex is incorrect. It should refer to criteria. Behaviour would be a criterion. Sexual orientation is not a criterion.

[*English*]

Mr. Nigel Flear: I'd like to go back to what Mr. McCutcheon was saying about the court challenges program. We certainly found it to be a very valuable program that allowed groups such as ours to dialogue about important charter issues. In this case, I don't believe we're faced with a charter issue, but certainly its elimination has limited the voice that groups such as ours have in the Canadian courts.

Ms. Kim Thomas: Quickly, just to respond to your question about the consultation, we have no recollection of an offer to consult. Stephen, I've just confirmed, took over this portfolio in January 2006. We would not have responded to that request for consultation if it had in fact appeared. Who knows? We did move our offices about that time, so maybe it was just lost in the mail.

The Chair: Thank you.

Mr. Tilson.

Mr. David Tilson: Madam Chair, I have two questions. The first one is to Mr. Tremblay and the second one is to Mr. McCutcheon.

Mr. Tremblay, I was most impressed with your testimony with respect to what you and your organization do to encourage people to make donations. I don't know whether you—and that's just you—have any recommendations with respect to either private or public...? I think what you do is wonderful. I think you've given wonderful examples of how people's attention can be drawn to the great need to reduce this waiting list for organ donations.

[*Translation*]

Mr. Richard Tremblay: Actually we do have some ideas. First, Madam Chair, members of the committee, I would ask you to consider this: we have been debating the new regulations since 11 a. m. All the while, people have been dying in Montreal, Quebec City, Toronto and London. These are the people who are on my mind. I hope that the committee will come to a decision quickly so that the waiting list doesn't get even longer. For the sake of the people on the waiting list, I urge the committee to clarify the situation as quickly as possible.

Members of the committee, recognizing the people who have donated organs is very important to families and to the grieving process. Let me say again that families who experience this recognition after the death of a loved one ultimately feel that their death was not in vain, that other people were given a chance to live and to enjoy a better quality of life.

Our association was totally disheartened to see the high cost involved to transport organs and medical teams to hospitals to perform transplants or to harvest organs. This was especially true in Quebec, where we are quite active and where we work with over 2,000 police officers across the province. We have put in place a transportation system that is unique in North America. A permanent team is in place at Pierre-Elliott-Trudeau International Airport in Montreal to welcome teams arriving from Toronto, London, Newfoundland, Nova Scotia and the United States and to accompany them to hospitals, saving valuable time in the process.

Every minute counts when an organ is harvested for transplantation. We have four seasons here and as you can well understand, during the winter, especially winters like the one we have just experienced, every minute counts. We cannot afford to lose a single organ. Unfortunately, statistics show that in 2007, there were only 135 donors in Quebec. The families of people on the waiting list for a new liver or heart are understandably concerned. Waiting lists are so long that finding a donor takes time.

There is work to be done and we believe that the recognition ceremony that we have been holding for the last 15 years in Quebec is an initiative that should be embraced by the federal government in all provinces. We would like the Governor General to agree to be the official sponsor of this ceremony honouring donors, just as donors from Vancouver, Nova Scotia, New Brunswick and other parts of Canada are honoured at the special, one-of-a-kind memorial in Sherbrooke . We need the federal government's support to move forward with this ceremony. By the way, I would just like to mention that we have consulted on this with our friends from France. Sometime in the next few months, a similar type of ceremony will be held in Paris to honour donors.

I leave here hopeful that your committee will come to a decision quickly and resolve this situation.

● (1255)

I remind you that while we do not have the required expertise to give advice, we do believe that we need to do everything we possibly can not to lose potential organ donors.

On behalf of the people waiting for a transplant, I thank you for giving this matter your prompt attention. Thank you very much.

[*English*]

The Chair: Thank you, Mr. Tremblay.

Our time is up now—

Mr. David Tilson: Madam Chair, can I make just one statement? I understand the time is up.

You may not have expertise, Mr. Tremblay, but you certainly have some good ideas. If you have anything in writing, perhaps you could table it with the chair in due course.

The Chair: It has already been tabled. We're translating it into English.

Thank you, Mr. Tilson.

Again, I thank you so much, Mr. Tremblay, for your presentation. It was very heartfelt.

I would like to thank each witness for coming here today and for the insightful comments. It was very valuable.

Ladies and gentlemen, the meeting is adjourned.

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