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Chair

Ms. Bonnie Brown

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● (1110)

[*English*]

The Chair (Ms. Bonnie Brown (Oakville, Lib.)): Good morning, ladies and gentlemen. It's my pleasure to welcome you to the 15th meeting of the Standing Committee on Health. This is pursuant to Standing Order 108(2), a briefing session on hepatitis C.

We welcome our witnesses today.

Our first witness is from the Canadian Hemophilia Society, Mr. Jeff Rice, the coordinator.

Mr. Rice, you have the floor.

Mr. Jeff Rice (Coordinator, Regional Resources and Hepatitis C Programs, Canadian Hemophilia Society): I'll be very brief. I'd like to send the regrets of the vice-president and chair of our hep C and HIV task force. He's the fellow who was supposed to be presenting today, but unfortunately he's not well, so I am sitting in. I coordinate the hep C program at the Canadian Hemophilia Society, at our national office in Montreal.

I've put some quite extensive documentation on the table, and there is a brief. There are three issues that I want to cover.

One of them, obviously, is opening up the 1986 to 1990 compensation package to all people who acquired hepatitis C through the Canadian blood supply, regardless of the date of infection. Obviously, we've always been supportive of that from the very beginning and continue to be. There are a lot of things that need to be worked out. We're very pleased to be able to be here to participate in any work that will be done in the future.

I will be very brief. I'm not the ideal spokesperson. John would have been much better than me. Perhaps if people have questions after I speak briefly, they could ask them.

The other thing I want to speak to is a scheme that we proposed about five or ten years ago, called BICS, which is the blood injury compensation scheme. It's only available as an English document at this point. I have put a copy on the table for reference. It was basically something we developed that would function as a mechanism for any type of blood-borne infection that someone might contract in the future. If there was an issue of compensation, then this scheme would exist and could apply to those situations.

The third thing I would like to speak to is hepatitis C generally. Although we've focused on compensation a lot, particularly in the last month or so and throughout the last number of years, the majority of our members are already compensated. In fact, anything that we're doing is for the broader population of people who are infected or potentially at risk for contracting hepatitis C. About 10% of our membership fall outside the 1986 to 1990 window, and those people could potentially be compensated should the program be opened up.

There are over 250,000 Canadians who have hep C. A third of them don't really even know they have it yet. Our idea has always been that you need to be diagnosed earlier so that you can begin treatment. Treatment is difficult. The cost of treatment at the beginning will be much less than if you are left for 20 years to have the disease linger, perhaps not even aware of it, and then you are positively diagnosed with hep C and have to go through the health care system and all the illnesses that might come along with it.

Obviously, the idea is to have some type of awareness program. I know that the government introduced a program about five and a half years ago, which was the hepatitis C prevention, support and research program. I think $50 million was allocated for that program. From our point of view, although there have been some moderate successes, it really hasn't been sustainable in any way.

With the creation of the new Public Health Agency, we're still waiting to see where hepatitis C will fit into that Public Health Agency. Obviously, we feel there should be some type of strategy similar, but not identical, to the Canadian strategy on HIV and AIDS.

Last year we received Health Canada funding. One of things that a group of community organizations involved in hep C work did was come together and draft a hep C strategy. There is a document on the table. Once again it is only in English, and that is simply because our funding was not significant enough to allow us to translate into both languages. We didn't feel we would need to at the time, but now that I am presenting here, it would have been great.

● (1115)

However, one other item that I will end on—and I don't want to sound alarmist—is that there is a certain degree of urgency needed in terms of opening up the compensation package. It has been six years or more since the original 1986 to 1990 agreement was introduced. People have died, and many people are sick and are still waiting.

Based on all the arguments that everybody is familiar with—I was fortunate enough to be able to observe one of these committee meetings before, and also to observe the exploratory debate that took place in the House maybe a month or so ago—there's a lot of information out there. I think people, and particularly those people around this table, are very aware. We have some great supporters, and I think it's time this happened.

The question I would have, which we've always had at the Canadian Hemophilia Society, is why did this not happen to begin with, and why is it taking so long now? Perhaps we'll never know the answer.

The Chair: Thank you, Mr. Rice.

Our second group of witnesses is from the Hepatitis C Society of Canada: Mr. Scott Hemming, national chairperson; and Mr. Charles Duguay, a board member.

I believe Mr. Hemming is going to present.

Mr. Scott Hemming (National Chairperson, Hepatitis C Society of Canada): My name is Scott Hemming. I'm the chairman of the Hepatitis C Society of Canada. I have to thank everybody and thank the committee for having us here today to speak on this important issue—an important issue to people infected, but I think as well to all Canadians who've looked for some sort of resolution to this situation, which has been ongoing for a number of years.

I think that when decisions were made in 1998 to include a certain group of victims and not include others, that was a very difficult position, obviously. For those outside the window, they felt it was unbelievable that they were never compensated but were led down a road to a variety of compensation packages that were established by either provincial governments or by the Red Cross.

It really takes a great deal of navigation, from our position as a non-profit organization, to help people find out where they actually fit. We almost have to ask about 20 or 30 questions of that individual—to find out which province they live in, when do they think they were infected—to actually steer them in the right direction. Then they go through a process of filing their claims, and that can be quite an extensive process. That's sort of the situation now.

To speak to what we would like to see in the future, we would like to see a comprehensive, equitable package for all people infected with hepatitis C, regardless of the date they were infected. When I speak to equitable, I think the only solution at this particular time is to look to the package that was established in 1986 to 1990. I believe there is a substantial surplus of funds there that will help all victims.

I think there will be a need for an actuarial study. I have to put a lot of emphasis on that. If I'm not mistaken, it's supposed to be ready for the court for June 2005. In my opinion, June 2005 is far too long. That's too long. The victims have waited six years, as Jeff has pointed out.

As a society, we were very pleased at the minister's announcement. I watched the announcement on a number of stations, but it really didn't indicate a whole lot as to what would happen. There were questions as to whether this would be a lump-sum payment, whether it would be a separate package for people outside the window, and we really didn't get a good sense of what was going to happen.

As a result of those discussions, our society, with one staff person, received approximately 200 calls a day from victims who believed that the 1986 to 1990 package was going to be dismantled and thrown away. That affects 9,000 individuals. Also, you have people who are outside the window believing they can apply today for compensation.

It was a huge gamut of confusion that was created within the community as a result of the announcement. Although being a positive one, it was still lacking a lot of information that I think the public was looking for, that people who were infected were looking for, and of course, that those people who were in the 1986 to 1990 framework were entitled to hear as well.

I wanted to mention that the messages that are coming, from a public relations point of view, should be a little more concise and to the point. It would help victims a whole lot and help our organization. It has almost put us at the brink of closure, it's that overwhelming. We cannot clear our voice mail messages fast enough in order to get to them. We do not have the resources to handle that volume of calls. If that could happen, we would certainly appreciate it.

Maybe a heads-up, more than that day from the minister's office, that there's going to be this announcement would be helpful as well. We want to be equal partners at the table, and I think that's really important.

● (1120)

There's one vital point that I wanted to make today concerning the sustainability issue of the fund. Section 4.02—I can't get dates right, but I think I've got that right—speaks to the federal, provincial and territorial liabilities of the fund. There are no liabilities, so should the funds be depleted, the liability is on the victims themselves. That is a very significant issue. Personally, this is my claims file since the year 2000, so you have an idea of what victims have to go through to establish their claims; it's very extensive.

The reason behind that is the sustainability. There's a fund council, there's a joint committee, there's a number of people involved in this fund who want to ensure its sustainability for the victims who were allowed in, which is a responsible approach. But it does create a tremendous amount of trees being cut down. I've been at it since 2000, it's now 2004, and I still haven't got all my claims settled. I don't think victims should have to do that.

It needs to be a user-friendly system. Removing that sustainability clause would make it a user-friendly system. There wouldn't necessarily be that criterion needed if the government today could say it would remove section 4.02. We could then immediately start working toward allowing people into the plan. We can start the process now as opposed to starting it in June, before actuarial studies are needed. I don't think the courts would be opposed to that at all, as long as the government takes that section out. Probably Bonnie would be a better person to ask about that.

From our position, we want to see fair and equitable compensation. We believe the sustainability clause is a drawback, will continue to be the drawback, and probably the courts will see in June, after the actuarial studies are done, that they'll need a commitment from the government to remove that sustainability clause. Why wait until June? Let's do it now and remove that section.

I do believe that's a commitment by the government. I don't believe there'll ever be a need to replenish or put any more money into that fund. It is a substantial amount of money now. I believe there's enough to allow the people who were left out...but that section has to come out in order for it to be successful.

That's what I wanted to say, so thank you so much for having me.

● (1125)

The Chair: Mr. Duguay, did you want to add anything?

Mr. Charles Duguay (Board Member, Hepatitis C Society of Canada): For me, what Scott is talking about is more the mechanics of how the system is working. I'm a guy who's looking at this whole system from the opposite end.

I was infected in 1985 after a motorcycle crash with an impaired driver. I got one unit of blood. It was whole blood that I got from a person in Sudbury. Basically, it came from his arm into mine. Within six years I was complaining to my doctor almost monthly about different things that I was feeling. Finally, in 1991 I was diagnosed with hepatitis C. At that time, there weren't that many people who knew that much about the disease. When I was told by my doctor in his very subtle way that I had hepatitis C, of course I asked the natural question, what's hepatitis C? He told me that it was a progressive disease of the liver. I said, okay, and what does that mean?. He said, there's no cure for it, so it means you're going to die. Unfortunately, I'm a pig-headed person and I didn't buy that.

My family life has changed completely. My wife will tell you on any day that I'm not the man she married. In two years I managed to drive my 16-year-old son out of the house. He left when he was 18. Now, I'm fortunate enough that we can sit together in the same room for two or three hours and talk like human beings.

I ended up in 1997 having a liver transplant. In the meantime, I lost a $50,000-a-year job at the steelworks as an electrician. I was on long-term disability at a considerable reduction in wages, and when my time came up, I was put on pension because it was cheaper to pension me off than it was to pay the long-term disability.

I've been looking at hepatitis C since 1991. I've been lied to, I've been put on the shelf, I've been ignored, I've been laughed at, and I was told to just shut my mouth and sit down. This is the first opportunity I've had an opportunity to speak to people in this position, and I'm happy to have that opportunity.

I wish I hadn't lost so many people to death due to hepatitis C. For most of them, if you read their death certificates, it'll say heart failure, congestive heart failure, liver cancer. But none of the death certificates say due to hepatitis C. Consequently, the information the government is getting is incomplete. Unless the doctors start reporting to the government on what is actually happening and what is causing these people to die, there never will be proper compensation; there never will be anything done to help out the families of these people.

For myself, I have been told that I'm a very angry man. And to be honest, I guess I am. I feel that 15 years—actually I'm up to 19 years now—of my life have been less than quality. With the drugs that the doctors were poking into me trying to get rid of the virus, it didn't make for a good daily life. After I had my transplant, within six months my liver was being affected again by the hepatitis C virus because they didn't clean all my blood or clean all my organs. So yes, I've been reinfected and my new liver has been reinfected, but I've been fortunate enough that the combination therapy has been working. My last PCR test said that I had less than 600 copies, which the doctor tells me means it is in remission, whatever that is.

I'm hoping things will begin to happen and that people who were left out of the compensation package of 1986 to 1990 will be looked at. Hopefully, the Krever commission will be followed, that all people will be compensated equitably.

● (1130)

For me, it's not going to make a lot of difference in my life. I'm hoping that whenever I do pass on, I have something to give to my children, because basically I've been, pardon the expression, screwed out of 15 years of work.

The Chair: Thank you, Mr. Duguay.

Mr. Charles Duguay: Excuse me for being coarse. I'm sorry that I've taken so long, but this is an emotional issue with me. I hope that I've touched your ears and your heart. Like Jerry Maguire, "show me the money".

The Chair: Thank you, Mr. Duguay.

We'll move on now to Ms. Bonnie Tough, who is a lawyer with Tough and Podrebarac. I understand this law firm has something to do with the administration of the fund.

Ms. Tough, perhaps you could explain how that works, because we're just not sure.

Ms. Bonnie Tough (Lawyer, Tough and Podrebarac LLP): I was invited to come down to answer questions, so I'm primarily here to answer questions. I have not prepared any submissions as such, but let me give you a little bit of background.

I'm a lawyer who represented, initially, the Hemophilia Society before the Krever inquiry, and subsequently represented the hemophiliacs involved in the 1986 to 1990 settlement. That gives me the hat as class counsel to the 1986 to 1990 hemophiliacs.

Following that settlement, there was a joint committee struck, appointed by the courts in Quebec, British Columbia, and Ontario to, I'm going to say, oversee, but in essence we are a liaison between the courts, which ultimately make the decisions, and the management or administration of the fund.

There are four members of that joint committee. I am one of those members. I'm here to provide any assistance I can, leaving aside whatever personal views I may have. I have a duty and a responsibility to the 1986 to 1990 class. That's an important factor.

Following the minister's announcement, the administration centre and all of the lawyers involved received numerous calls from members of the 1986 to 1990 class, some very concerned that this announcement would impact on the moneys available to pay their claims either now or in the future. You'll appreciate that the settlement is structured in such a way that if the disease progression for any individual gets worse, they can come back and get further compensation if they're unable to work or if they have other needs.

We put a notice on the website for the 1986 to 1990 simply indicating that we will be working to ensure there's no negative effect on the 1986 to 1990 entitlement, that we will meet with, and have met with, lawyers for the Government of Canada to discuss the minister's announcement, and that our first priority remains the interests of the 1986 to 1990 group.

That's it. If you have questions, I'm happy to try to answer them.

The Chair: I noticed you taking notes when Mr. Hemming was speaking. Did you want to respond to any of his points?

Ms. Bonnie Tough: If I may, I was taking notes because Mr. Hemming was speaking about some of the things of which I perhaps have a more detailed knowledge.

The process right now is ongoing. We have a settlement agreement that is encompassed in a judgment of the three courts. That judgment obliges the joint committee to lay before the courts, in June 2005, a sufficiency study. That sufficiency study is ongoing as we speak here now, and there are two parts to the sufficiency study.

One part is what they call the medical modelling. There is a disease progression. There is a balancing to be done between the number of people in whom we can anticipate the disease will go into remission—or, indeed, they're now on occasion actually using the word “cure”, I understand. And then there are other people who will progress very rapidly, become very ill, and die from the disease. That modelling is a necessary input to the actuarial study, because the actuarial study is in essence taking the numerical modelling and asking what the impact is on the moneys in the fund of the disease progression that we are now seeing. That, as I say, is step two.

The actuarial study has been started, but they are awaiting the results of the medical modelling. The medical modelling is ongoing, and is obviously all in the hands of specialists who are doing this modelling.

We would hope to have all of those studies completed and the report ready for the court in June 2005 as the outside date, as we're required to do.

People have talked, as did Mr. Hemming a few minutes ago, about a substantial surplus in the fund. The extent of the surplus, if any, is not going to be apparent or anything other than speculation until the actuarial study is completed. It's simply guesswork at this point in time to speculate on the size of any surplus.

The 1986 to 1990 settlement is premised on—and Mr. Hemming made reference to this in terms of the sustainability; the lawyers describe it somewhat differently—the 1986 to 1990 class members having taken the risk of insufficiency. If there is not enough money in the fund, their benefits will be cut back. There is no more call to be made on the federal, provincial, or territorial governments, and it is that risk to the individuals in our class that has caused, for example, the sufficiency study that is ongoing. But we also had certain payments that we held back, for which we said, until the courts are satisfied there is enough money, you're only going to get 70% of your income lost, not 100%.

Those caps, as we call them, have recently been lifted, which is obviously a positive sign. The courts have ruled that they be lifted. But until the actuarial study is done, we really can't speculate on the size of any surplus.

● (1135)

The Chair: Thank you very much, Ms. Tough. That's quite enlightening. Thank you for your testimony.

Our next witness is testifying as an individual.

I welcome you, Ms. Tina Lyon. You have the floor.

Ms. Tina Lyon (As Individual): Madam Chair, committee members, members of the media, ladies and gentlemen, fellow victims, years ago our Canadian tainted blood disaster left thousands of us infected with hepatitis C. Our victims were divided into two classes. One group would be helped and the other was told to quit whining. The 1986 to 1990 group received help through a federal–provincial–territorial government agreement, but today we are here to talk about the other group—our group, my group.

Most provinces and territories and our federal government have forgotten our pre-1986, post-1990 tainted blood hep C victims. A few provinces, including my home province of Ontario, have thankfully provided some limited assistance, but a lot of our provinces have not. The September 1998 federal–provincial–territorial undertaking designed to help our pre-1986, post-1990 group with care and not cash, treatment and not payment, has been an utter failure. I have not been provided with this care. My suspicion is that they hope we die quietly.

Our victims have been patient and understanding. Reluctantly, we have been forced to tell and retell our stories to all levels of government, our friends and families, and the media. It is our hope that our Canadian government will come forward, do the right thing, and help us victims with fair and ethical treatment. In 1997, the Honourable Justice Horace Krever said, “Compensating some needy sufferersand not others cannot, in my opinion, be justified”.

My story is not unlike that of any of our victims. My life was rather normal until the birth of my son John in 1985. Massive transfusions saved my life; however, years later I would discover my hep C tainted blood. I eventually returned to work, but my run-down state led to my last working in October 1990 in gainful employment. Richard, my oldest son, attended Carleton University from 1989 to 1994, and this year, 2004, his further learning debts were retired. What a coincidence. Now, in 2004, our youngest son John is starting at Carleton University. I am sure that many of our forgotten victims can tell similar stories.

There is a difference. I live 80 kilometres from Ottawa, where these hearings are taking place, and I feel I have the responsibility to tell our victims' stories to our government officials face to face. I must admit that I am not comfortable discussing personal problems with many people that I have never met before; however, I believe it is important to put a face to this tragedy.

Through the years, we have met numerous times with our various federal members of Parliament, our provincial member of Parliament, and Health Canada officials. We have written dozens and dozens of letters and have even received some wonderful-sounding replies. We have literally made hundreds and hundreds of phone calls in attempting to prompt action to help our victims. Until recently, it appeared that our victims' efforts were futile.

I must mention the continuous help of my husband Ron and my family, and the keen observations and assistance of our fellow victims Keith and his family, both of whom are with me today, and the various media outlets across Canada who report, it seems almost daily, our victims' hep C stories. On behalf of our victims, I sincerely thank them for standing with us.

I leave you with a small story from the heart. One of Ron's favourite elderly aunts, Mrs. Edna Allman of Almonte, passed away three years ago at the age of 94. She lived a fine, full, and interesting life. From the first word of tainted blood hep C victims, and seeing how it was affecting my life, she became an information gatherer to assist me, part of her family. She watched TV, she listened to radio, she read newspapers daily, and religiously reminded Ron and me of what was said, or had the clippings from the paper.

● (1140)

As I said previously, my story, Keith's story, other victim's stories have a lot in common. We have waited a long time for promised help, and I believe we deserve government help.

Thank you for listening and reconsidering the plight of our pre-1986, post-1990 tainted blood hep C victims.

The Chair: Thank you very much, Ms. Lyon. I think you've succeeded in putting a human face on this disease and bringing it to our meeting.

Ladies and gentlemen, we'll proceed now to the question and answer section of our meeting. We'll begin with the critic from the official opposition, Mr. Steven Fletcher, who will have 10 minutes.

Mr. Steven Fletcher (Charleswood—St. James—Assiniboia, CPC): Thank you very much, Madam Chair.

My first question I think I'll throw out to any of the witnesses, but particularly to Ms. Tough or Mr. Rice.

There have been repeated calls to open up the compensation fund prior to November 2004. In an announcement prior to November 2004, the health minister indicated that such action would be beyond the power of the federal government since the fund didn't belong to it. When that was said, it inferred that the federal government had no authority to change the criteria for the compensation.

I guess I'm concerned that there may still be a possibility that the federal government does not have the authority to take action or that discussions may result in the administrators of the fund deciding not to open it up to all victims. This is of concern to me, and I would assume it's of concern to you.

● (1145)

Ms. Bonnie Tough: Let me try to answer that, if I may.

The judgment of the courts provides, as I said earlier, for the study as to whether or not there's going to be a surplus, or a deficiency, for that matter. The judgment provides that the court has four options in respect of any surplus.

One option is to pay it directly to the class members in the 1986 to 1990 class. The second option is to pay it for the benefit of the class members of the 1986 to 1990 class. The third option is to leave it in the trust fund, to in effect await further time and further studies. And the fourth option is to return it to the federal, provincial, and territorial governments.

That is initially a decision that is to be made by the courts, and obviously interested parties would have the right to make submissions before the courts as to which of those options should be pursued. But even if there is a surplus, it's not a case simply of the money being there for the federal government or for any government to direct.

Mr. Steven Fletcher: Mr. Rice, do you want to make a comment on that?

Mr. Jeff Rice: Not having the legal background, I can't really speak much to that.

Mr. Steven Fletcher: Okay, but would we all agree that surplus or no surplus, it's almost not of primary importance. The issue is the principle that these people should be compensated. I would assume that you would agree with that—the money should be found, one way or the other.

Mr. Jeff Rice: This I certainly would agree with. Obviously, where there's a will there's a way. We have the legal argument and the legal side of things. It really needs to be worked out. But if it's something that people feel is the right thing to do, then there has to be some way to get it done.

Mr. Steven Fletcher: I want to say that I really appreciate what you've gone through, particularly Charles and Tina—all the victims. The official opposition and the other opposition parties have worked very hard, I think, on your behalf to try to open up the fund.

You guys have gone through so much, families have been destroyed, people have died. We have the Parliamentary Secretary to the Minister of Health here, and I wonder, if he were to apologize on behalf of the government for all the suffering you have gone through, would you accept that apology?

Would he provide that apology?

The Chair: I believe this question is out of order.

Mr. Fletcher, you are entitled to ask questions of the witnesses, but I don't think it's fair to implicate other members around the table in your questions, nor is it fair to the witnesses to ask them to answer a question that is speculative at best.

Mr. Steven Fletcher: Okay, Madam Chair, then my point is that there is someone here officially on behalf of the government who could have that.... But I'll take it off the table.

Maybe I'll just ask this of the witnesses. If the government were to apologize for all the misery it has caused you, would that be good enough, or would that never fill the gap?

The Chair: Once again, that question is speculative—“Should the government forgive...?”

● (1150)

Mr. Steven Fletcher: That question was to the witnesses.

The Chair: Yes, Mr. Merrifield.

Mr. Rob Merrifield (Yellowhead, CPC): On a point of order, I believe it's up to us to ask the witnesses a question. It's not for the chair to ask whether it's out of order. If the witnesses cannot answer it, they can refuse to answer it. But the question can be put, I believe. I don't think we can call that out of order. They're here to answer the questions, and we should allow them.

The Chair: I still feel, in answer to that point of order, that I should at least give the witnesses the chance to understand that they don't have to answer speculative questions.

Mr. Rob Merrifield: That's fair.

The Chair: We have a second point of order from Mr. Thibault.

Hon. Robert Thibault (West Nova, Lib.): Thank you, Madam Chair.

I'd remind all members, through the chair, that in our first meeting when we looked at the orders, the procedures, we jointly and unanimously asked the chair to keep the meetings focused and keep them on track according to what we're here for. We talked about that when we had the minister coming, and when we had others.

Today we have witnesses here, very kindly and appreciably. They're bringing us the opinions of people who are very concerned about this so that we may help. Bringing up questions of whether the government should apologize or not is completely off track from the purpose of the meeting, and I think the chair is right to keep this meeting in order.

Mr. Steven Fletcher: That's not a point of order.

The Chair: It's not a point of order. I'm sorry, we entering debate.

I would just ask the person who has the floor, who will not lose any of this time, to be careful about not asking “If this happens...” or “If that happens...”. It usually isn't acceptable.

Mr. Steven Fletcher: We're talking about compensation, trying to mitigate the suffering the witnesses have gone through, which has been tremendous.

Would it be helpful to you as part of the healing process to have, along with monetary compensation, recognition from the federal government that it has screwed up big time?

Mr. Charles Duguay: May I answer that? I'm speaking as Charles Duguay, not as a member of the Hepatitis C Society or anything else.

Personally, in 1995 all I wanted was for somebody to say, “We screwed up big time, and we're really sorry”. But as I said, I've been lied to, I've been told to sit down and shut up. I have had my humanity taken from me. Now it's a matter of money. I was willing to deal with that at one point in time, but I was not aware at that time of what I was willing to accept. I don't think my family deserved what they got.

The person who caused this initially got a $1,000 fine and lost their licence for six months. For me, it's cost me far more than $1,000—and this is 20 years that I'm talking about. So compensation does not seem to be fair, as far as I'm concerned.

Thank you.

Mr. Steven Fletcher: Maybe I'll ask Mr. Rice.

Do you think it would help your members to get some sort of acknowledgement from the government that it could have handled the situation much better, an acknowledgement that people have died, families have been destroyed, lives have been wrecked, that the government is sorry and will back that up with monetary compensation and an acknowledgement that the government has not done what Canadians expected it to do?

Mr. Jeff Rice: To the degree, as you mentioned, of people healing and moving on, that would be helpful.

Historically there always seems to be a reluctance of governments at whatever level to acknowledge responsibility, to say “We were responsible, and we're sorry”. It's rare that this occurs, and it seems to take quite a bit for it to happen.

Many people need to hear that. And of course, the words are fine to hear, but also people need to see the money, because that's what's going to support them as they become more ill. That's what's going to support the people they leave behind when they die.

So I think an apology would be great. I won't hold my breath.

Mr. Steven Fletcher: Ms. Lyon, I'll pose the same question to you. You don't have to answer, as the chair has acknowledged, but along with monetary compensation, would an apology from the government help in dealing with your suffering?

● (1155)

Ms. Tina Lyon: Well, my member of Parliament has already apologized to me for what I've gone through.

Mr. Steven Fletcher: But on behalf of the federal government, because it is the federal government that has been denying the compensation—

Ms. Tina Lyon: Right.

Mr. Steven Fletcher: —would it be helpful for you to get an acknowledgement from the Minister of Health that his predecessors and his government haven't acted appropriately on this file?

Ms. Tina Lyon: Yes.

Mr. Steven Fletcher: Yes? Okay.

Thank you, Madam Chair.

I would like, on behalf of the official opposition, to thank you all for coming and sharing this, and I hope you will get the compensation and the apology some day in the future.

The Chair: Thank you, Mr. Fletcher.

Our next questioner will be Madame Demers.

[*Translation*]

Ms. Nicole Demers (Laval, BQ): Thank you very much, Madam Chair.

I will put my question in French, but the witness can answer in English.

Mr. Rice, you have to understand that I am sympathetic to the plight of hemophiliacs. My 34-year-old son is a hemophiliac. Therefore, it's very important to me that adequate care is available.

Could you tell me...

[*English*]

The Chair: Madame Demers, just wait a minute; I'm not sure everybody is hooked up. Would you begin again?

Ms. Nicole Demers: I'm sorry. I want to use the right terms, so I want to make sure. Sometimes I might have a term that's not proper.

The Chair: That's why we have translators, to assist you to make the clearest presentation you can.

Ms. Nicole Demers: I want to make sure I say the right thing.

The Chair: You can go ahead, Madame Demers.

[*Translation*]

Ms. Nicole Demers: Thank you very much, Madam Chair.

I want to thank each and every one of you for being here this morning. As I was saying to Mr. Rice, I'm very sympathetic to the concerns of the Canadian Hemophilia Society because my 34-year-old son is a hemophiliac.

Mr. Rice, can you tell me how much funding you would need to carry out the type of programs you briefly described, that is prevention and support programs for persons diagnosed with this disease?

[*English*]

Mr. Jeff Rice: If you were to look at...and unfortunately it's only available in English, but as I said, last year we received money from Health Canada's hepatitis C prevention, support, and research program to gather community groups together who are involved in work around hepatitis C, and we developed a strategy. I don't have with me the figure as to what would be required to cover that, but it would be available in the document on the table.

[*Translation*]

Ms. Nicole Demers: I see.

I would also like to inform the witnesses that the Health Committee has unanimously agreed to consider compensating victims infected before 1986 and after 1990. Many of us were not here when these decisions were made, but I think you can count on everyone's support and efforts to move this matter forward.

Ms. Tough, how many people currently receiving compensation would be affected by the decision to extend compensation to persons infected before 1986 and after 1990? Earlier, you stated that many people had called you to voice their concerns and to inquire if this decision would affect their compensation. Do you have that information for us?

● (1200)

[*English*]

Ms. Bonnie Tough: There were a number of people in the 1986 to 1990 group who have called and have expressed a concern that their entitlement might be diminished because the fund has “opened up”, as the media has described it. As to the actual number of people who have called, I can't tell you that. Some have called me; some have called other lawyers involved; some have called the centre.

In terms of people being affected, our goal as a joint committee would be to ensure that there is no negative effect on anybody in the 1986 to 1990 group; that anybody who is in that group of 1986 to 1990 will receive the compensation they should receive pursuant to the judgment and the settlement; and that they not be negatively impacted in any way by payments that might be made to others.

Ms. Nicole Demers: But do you have a number of people who are remaining in the 1986 to 1990 category?

Ms. Bonnie Tough: I'm sorry. Do you mean the number of people in the 1986 to 1990 group?

Ms. Nicole Demers: Yes.

Ms. Bonnie Tough: There are various ways to calculate it, but including the hemophilia group...and as Mr. Rice has said, almost all of the hemophiliacs are in the 1986 to 1990 group, because they had blood in that period of time. The total number of primarily infected—and that's leaving aside family member claims and dependant claims and things like that—is approximately 4,200, but we continue to receive new claims as people are diagnosed for the first time.

Ms. Nicole Demers: How many infected people will benefit from the removal of the cap, and how much money does it mean?

Ms. Bonnie Tough: We do have that information. I could provide it to you, but I do not have it here. It would be anybody who was receiving a loss-of-income payment. I just don't have the number that would entail, but I could certainly provide it to you. It was a document we filed with the court—there was a small actuarial study done—and I will provide it to your office.

Ms. Nicole Demers: Yes, because it might make quite a difference in the money that will be left over to compensate the victims before and after.

Ms. Bonnie Tough: It is one of many factors. The cost of treatment and whether provinces pay for treatment or whether the fund has to pay for treatment is another factor that is very important. The medication is very expensive and is certainly not getting any cheaper as time goes by.

Ms. Nicole Demers: And as the manager of the fund yourself, would you say the managers are open to negotiation, or is there a closed mindset, because you really want to make sure the 1986 to 1990 ones are compensated correctly?

Ms. Bonnie Tough: Our focus is on ensuring that the class members from 1986 to 1990 receive the compensation to which they are entitled and that they have the maximum protection so that when they need the money it will be there. We have said we are prepared to sit down and have sat down with the representatives of the federal government to talk about this. We will do that, but our focus is on protecting our class members.

The Chair: Ms. Demers, that's all your time. I'm sorry, was there a question in the air?

Ms. Nicole Demers: No.

The Chair: Thank you, Ms. Demers.

Next is Mr. Thibault, and then Mr. Merrifield.

Hon. Robert Thibault: Thank you, Madam Chair.

Once again, I'd like to welcome all witnesses to come forward and bring us some very personal stories and tell us what this situation means from the point of view of individuals as well as groups. I think the information you bring forward helps to share and to get Canadians to understand your cause and your concern. While we see a few people here, many tens of thousands of people are out there in the country whose faces you represent. We thank you very much for doing this, and doing it in a very able way.

I'd like to remind everybody of the motion that was put forward by this committee: “That this Committee, in recognition of the recommendation of the Krever Inquiry and the large surplus in the federal Hepatitis C compensation fund, urge the government to extend compensation to all those who contracted Hepatitis C from tainted blood”. That was carried unanimously by all members of this committee. It was moved by Mr. Merrifield.

While the wording doesn't say it, I'm sure Mr. Merrifield would agree that when we were talking about surplus, we understood it to be actuarial surplus and not the apparent surplus seen by looking at the amount of money in the fund now. We have to understand that there are people who are yet to become beneficiaries of that fund, whose disease will progress to a point where they will be beneficiaries. There are people who are beneficiaries now whose needs will increase as time goes by. The amount of funding needed would be based on the schedules established by Madame Tough and a whole group of other people representing all classes, such that, according to the schedules, as their needs increase, the funds allocated to them will increase. It could be for 70 years. There could be 70 years of allocations still from that fund. It's that actuarial surplus that's important.

I'm glad this was clarified, because we've had a hard time getting across to people that we, as government—and I'm not a member of the government and can't apologize for the government; I'm a member of Parliament, as are all members here—cannot change the terms of that trust. That trust is now under ownership and kept in a trustee situation for the 1986 to 1990 recipients.

What the minister has done, pursuant to that and to a lot of requests from a lot of people, including all of those present as witnesses and their representatives, is issue a press release to which we are referring. I won't go through the preamble, but given all of these factors—and that's what I was outlining:

> ...we have therefore decided that it is right and responsible to revisit the decision and begin discussions on options for financial compensation to those who were infected through the blood supply before 1986 and after 1990.
>
> ...
>
> Discussions on developing options for compensating Canadians infected with hepatitis C through the blood supply before 1986 and after 1990 will commence as soon as possible but are expected to take several months and involve many players. There will be discussions with the lawyers who oversee the 1986-1990 Settlement Agreement and with the lawyers of Canadians infected with hepatitis C through the blood system before 1986 and after 1990, and the provinces and territories.

As you can see, what the minister is saying...and he's not here to explain it himself, but what I understand from it is that when he's talking about looking at options, it's not that options are included or none of them are eliminated, but we have said as a committee, and many people have said, including people at the end of the table, that there may well may be an actuarial surplus and that we can enter into those discussions. The minister can't state today, the Prime Minister can't, and all of government together can't say those funds will be allocated or conditions will be removed from those funds. It's not our job to do that. Requests to do it can jointly be put, or independently be put, but generally would be more positively put if they're jointly put to the court. The press release recommends those discussions.

That doesn't mean there's not an opening or a possibility of other ways being found. That's where the term “options” comes in.

Before I ask questions of the witnesses, I'd like to—

Some hon. members: Oh, oh!

● (1205)

The Chair: You'd better hurry up.

Hon. Robert Thibault: Well, I'd just like to say—and maybe I'll come back later—that it was suggested that I, on behalf of government, make an apology. If I could, I would, maybe. To be political, I would apologize to Canadians for the mishandling of the blood system between 1984 and 1993 when another government was in, but that would be a cheap political shot, which I will not take.

I will say with pride that the moves begun by this government began in June under the leadership of Mr. Dosanjh and with the cooperation of all this committee.

Merci.

The Chair: Thank you very much. That was perfect timing, five minutes on the nose.

We'll go now to Mr. Merrifield, who will be followed by Ms. Dhalla.

Mr. Rob Merrifield: That was a very interesting question. It's obvious that you're a politician.

But I appreciate the opportunity to have you come here.

My first question is this. First of all, do we compensate or do we not compensate? That was the initial thought behind my motion before this committee. It's a very simple question. You either compensate everybody or you do not.

When you look at the compensation between 1986 and 1990, it was for those with hepatitis C. All of those who were infected with tainted blood outside that window were compensated if they contracted HIV. I think this is overlooked by a lot of people. You're not only discriminated against because of the timing of when you contracted this disease, between 1986 and 1990, but you're discriminated against because of the kind of disease that you've caught because of this blood. It's a double mistake, if you can look at it from that perspective. As Canadians, we all should feel bad about that.

At any rate, what do we do about it? We have to make the decision on whether we compensate or do not compensate. If there's money left over in the fund, we should compensate, and perhaps even more than that.

My first question is to you, Ms. Tough. The money that was set aside from 1986 to 1990 was roughly based on 22,000. It was speculation at that time, and numbers were thrown around, but about 22,000 individuals were proposed to be infected. We know that only 5,000 or so were actually compensated and roughly another 5,000 were outside that window. We may be out on some numbers, but not that far.

Do you feel that there still would not be enough money? Your suggestions were that the actuary may show there isn't enough money. I don't know how we can justify that thinking.

● (1210)

Ms. Bonnie Tough: In response, let me talk about the numbers for a second. Although the number 22,000 was the result of one of the epidemiological studies, the number that was used in the original actuarial studies and was the focus of the court's decision was a low of 6,800 and a high of 9,200. I don't have it exactly, but it was in that range. As you can appreciate, the epidemiological evidence was not completely uniform.

The actuarial study that was used in 1999 for court approval of this settlement had a deficiency. It was a small deficiency, but there was a deficiency at the end of the day. It was $50 million or $60 million. It was small in comparison to the overall size of the fund. You are right that we have fewer claimants in the door, at this point in time, than was anticipated at the time of the settlement approval in 1999.

We cannot lose track of the fact that they continue to come in the door and continue to be diagnosed with hepatitis C for the first time. People who had transfusions in 1987-88 and for the first time go for a medical for life insurance are diagnosed in that manner. They have basically been asymptomatic. There are still a number of people coming in as fresh claims to the centre.

In addition, the original actuarial work that was done was based on a disease progression that was taken from medical literature because we did not have a cohort of people who we had information on. When the medical modelling is done, they will now use the statistics generated from the centre, which is in reality our cohort of people. That may be better or it may be worse. Our cohort may be older, younger, healthier, and getting better treatment. It's one of the many variables that causes me to say that we can't speculate at this point in time on what the surplus will be, if any.

Mr. Rob Merrifield: By June we'll know, and we'll have the actuarial study.

Ms. Bonnie Tough: By June 2005, we should have the actuarial study.

Mr. Rob Merrifield: And we'd probably have a pretty good idea of it right now, because $1.2 billion was in the fund at that time and there's $1.1 billion or something left if you add the provinces' share now. Is that right?

Ms. Bonnie Tough: If you add back the unfunded portion of the provincial liabilities, you're probably up in that range.

Mr. Rob Merrifield: Yes, it's roughly $1.1 billion, give or take a few dollars.

My next question is to Charles and maybe Tina. How much money would you get if they opened up the window, and how much money have you got from Cash for Care?

Ms. Tina Lyon: Cash for Care? Nothing.

Mr. Rob Merrifield: You got nothing?

Ms. Tina Lyon: No.

Mr. Charles Duguay: Me, I got $25,000 from the Ontario government and I got $6,000 from the Red Cross settlement, so I've got $31,000 in the last 20 years. Well, if you go back as far as 1995, when I first heard the Krever commission and what not was going on...from 1995 until now I've received $31,000 and I've lost $50,000 a year.

● (1215)

Ms. Tina Lyon: I also received that from the province, but that wasn't the Care not Cash.

Mr. Rob Merrifield: It was Cash for Care.

Ms. Tina Lyon: Yes, what he was talking about was not out of that program. Out of the Care for Cash program I've received nothing.

Mr. Rob Merrifield: That was a provincial government saying we're going to do the right thing regardless of what the federal government says. Is that right?

Ms. Tina Lyon: Yes.

Mr. Rob Merrifield: And they gave you that.

How would they look at this now? Maybe this is a question more for the lawyer. If they opened up the window, what would the province do as far as their part in the fund is concerned?

Ms. Bonnie Tough: What the provinces would do is completely hypothetical, and I wouldn't purport to speak for the provinces.

My understanding is that across the country there are provinces that have done nothing, there are provinces that have paid significant sums of money and have obtained releases from people, and there are other provinces that have paid moneys but have not insisted upon a release for payment. It is a quilt of different patterns across the country.

Mr. Rob Merrifield: It's a dog's breakfast.

The Chair: Thank you, Mr. Merrifield.

We now have Ms. Dhalla.

Ms. Ruby Dhalla (Brampton—Springdale, Lib.): Thank you very much.

It's been a pleasure and really an honour to have so many of you, especially Tina and Charles, tell your stories. I know, being from a health care background, what it is not to know many of us around this table yet to open up your hearts and tell us a little bit about your life. I want you to know we greatly appreciate it.

I just want to start off by saying that while it was implied earlier on by the official health critic for the opposition that the government didn't care, I know, as someone who's a new member of the governing party, that I am deeply touched by your stories and that there are many people on the government side who do really have empathy about what's happened.

I don't think anyone would ever intentionally want anything like this to occur, but it has occurred, and we now have to deal with the issue of compensation. To be honest, I think no amount of money ever given will compensate for reducing the quality of life of the many people who have been affected, but there are people in the governing party who are really empathetic and who do have deep concern and deep compassion about what's happened.

My question, first of all, is to Mr. Rice. You mentioned earlier on when you were speaking that there is a hep C prevention and support program in place, that something along the lines of $50 million has been allocated, but that it wasn't sustainable. You were looking to see what role the Public Health Agency would now play with its program. Could you just perhaps elaborate on that?

Mr. Jeff Rice: I believe the program was originally announced for five years but is in its sixth year, so it's been extended for one year. We don't know what will happen around that program at the end of the government's fiscal year. It happened last year that we didn't know, and again individuals and community groups are scrambling to find out whether they'll be able to sustain their activities beyond that. Once again we'll be waiting to see if that program will be extended and, if indeed they develop a strategy as we and other community groups suggest, how it will fit into the new Public Health Agency.

Ms. Ruby Dhalla: And has that information in regard to a long-term strategy been forwarded to the Public Health Agency?

Mr. Jeff Rice: Oh, yes. I can't say that's how far up the chain it has got to, but the people we work with are program consultants, and their managers at the hep C program are certainly aware. I would think they would have shared that information with the people above them who make other decisions.

Ms. Ruby Dhalla: If it's possible, Madam Chair, can we have some of that information perhaps given to the clerk so she can disseminate it to us as committee members? I would really be interested in seeing what the proposal for a long-term project is.

We can talk about a variety of conditions that occur to people, but to actually put a human face and story on them really means a lot. Perhaps, Charles, we can start off with you. The second question is this. If you can, tell us what an average day is like for you. Also, how much money do you spend on a monthly basis for some of the costs that are required to care for hep C?

Mr. Charles Duguay: Right now, since I've had my transplant and since the combination therapy has worked for me, I live a fairly normal life. But there was a period when I worked four months out of the year and during the other eight months I was off, extremely ill. From working eight hours a day, spending eight hours with my family, and sleeping eight hours, I had regressed to a point of sleeping 20 hours a day. I'd have to set the alarm to get up to make supper for my wife so she would have something to eat when she came home. Immediately after supper, I was sitting in front of the television sleeping again.

As I said, she basically has had no life for 15 out of the last 20 years. Fortunately for me, she's still with me. I think she's the exception rather than the rule, because I know a number of people who have been infected with hepatitis C who are now on their own. Their families have left them and right now they're just too sick to care.

● (1220)

Ms. Ruby Dhalla: How much money would be spent on medication in terms of managing hep C for you?

Mr. Charles Duguay: Because I never paid for it, I really don't know. I had a major medical plan with the steel company I worked for, and it was covered by my major medical plan. I understand the anti-rejection drugs I'm taking right now cost the Ontario government in the neighbourhood of $22,000.

They were talking about delisting that, and I mentioned it to my member of Parliament. I said if that was the case, they might as well just take me out and shoot me, because there was no way I could afford $22,000 a year in medication and still live.

Ms. Ruby Dhalla: Tina, if you could, please just tell us a little bit about yourself, what a day is like, and also how much you would spend on managing hep C for yourself.

Ms. Tina Lyon: Right now I've levelled off and I'm okay for a while. I have gone through the treatment, and that was very expensive. I was lucky; we had a drug plan, but our share was still a lot, seeing as I wasn't working. I had to quit because I couldn't function at work. My daily life is rather boring because I can't do too much.

The Chair: Thank you, Ms. Dhalla.

Our next questioner will be Mr. Carrie.

Mr. Colin Carrie (Oshawa, CPC): Thank you very much, Madam Chair.

I'd like to start off by saying that so far, from my point of view, the round of questioning is missing the whole point. Is it right or wrong to compensate these victims? It seems we've been listening to excuses about the fund and how much is going to be in there or how much is not going to be in there. What I'd like to see is us moving forward and just getting on with it.

Mr. Hemming, you mentioned that if we were able to get rid of a certain section 4.02, it would allow the government to get moving forward on this.

Mr. Scott Hemming: Thank you for addressing the question to me, because I've been dying to answer some of the questions that have come up here.

First, let me talk to Mr. Fletcher about his question, because I think it's really critical, and it's been mentioned by other members. It's the question of why the government is operating at arm's length from this plan and why it is being administered by the courts.

From a victim's point of view, my point of view, having been in the 1986 to 1990 plan, having been affected at the age of 20 years old, and having had my wisdom teeth extracted in Halifax, Nova Scotia, I can tell you about the frustrations from this 1986 to 1990 plan and how they hold onto this money.

Now, my point is that I've contacted members of Parliament—my good friends in the Liberal Party and my good friends in the Conservative Party—and my good friends who have been elected at a variety of levels, and they've said, we can't help you with this. I send countless letters to people and they say, we can't help you, Mr. Hemming, and do you know why? It's because this is at arm's length from the government. We took $1.1 billion of the Canadian taxpayers' money—there you go—and we can't help you at all with it.

Mr. Colin Carrie: I'm not an actuary, but I just did a little math while I was sitting here. You mentioned the number 4,200 people between 1986 and 1990. If you just divided that $1.1 billion, that would be $2.6 million per person. Now, if there are another 5,000 we're talking about, you're still talking approximately $1.3 million. I'm wondering, Ms. Tough, how much does it cost—if you know—to administer this fund per year? How much is actually going out for the administration of it and not going out to victims?

● (1225)

Ms. Bonnie Tough: The administration in the last couple of years has been less than 10%.

Mr. Colin Carrie: Less than 10%, so we're talking—

Ms. Bonnie Tough: Sorry, it is less than 10% of the amount paid out. Last year the total cost of administration was less than 10% of the amount paid out last year to claimants.

Mr. Colin Carrie: Do you have a number?

Ms. Bonnie Tough: Yes, it's on the website.

Mr. Colin Carrie: I was just curious to know how much is being actually paid out to administer the fund and not going to the victims.

Ms. Bonnie Tough: The administrative cost in the year ending March 31, 2004, with roughly $60 million in claims paid out , was roughly $6 million in expenses.

Mr. Colin Carrie: I just see this huge amount of money, and I was wondering if you had any other ideas on how the government could move forward. You mentioned section 4.02. By the time this money goes out, more victims will have died. Do you have any other ideas about getting this moved along a little more quickly?

Mr. Scott Hemming: Obviously, that sustainability clause is a big issue.

Mr. Colin Carrie: Okay.

Mr. Scott Hemming: I think the courts would look at this much more favourably if the government were to agree to lift that particular section.

One thing I look at is the discussions between the federal, provincial, and territorial ministers. We talk about national day care programs and a national pharmacare program, and these discussions have been going on for years. How long will it be before victims see compensation? When I hear of federal-provincial-territorial discussions, I almost have a heart attack.

From my perspective as a chairperson representing 6,000 people infected with hepatitis C, I have a hard time going back to my constituents and saying this is a really good announcement. I was hoping we would have something concrete and conclusive, so that this section would be removed. I think everybody knew that the courts would ask for this eventually.

Bonnie, this is speculation on my part, but I believe the courts will ask for sustainability at the end of the day. In June, when the courts look at it, I think they'll say this has to be sustained by government. Let's make the move now.

I think this is great. I honestly believe the Conservative Party, the Liberal Party, the New Democratic Party and the Bloc—everybody is working together on this. I don't believe there's any separation. I watched the debates on television; I watched the comments by the members. It really was super to watch everybody. Hedy Fry was so articulate and spoke so well to the issue, along with Mr. Goodyear and his points, and Mr. Fletcher. I really believe that everybody is on the same page, so why don't we just try to make this happen as quickly as we can? You know, that's really the bottom line.

Thank you so much for the question. That's really the bottom line. If we can remove that section, I think things can happen much faster for the victims.

The Chair: Thank you, Mr. Carrie.

Ms. Chamberlain.

Hon. Brenda Chamberlain (Guelph, Lib.): My question is also for you, Scott. You talked about better communications. Tell us more about that, what can be done in that area, because that too is very important, obviously.

Mr. Scott Hemming: Absolutely.

I think Jeff Rice from the Hemophilia Society brought light on a strategy. In part of the strategy, you would have a communications piece. I think it was approached very quickly by the government of the day, because there was tremendous pressure to rectify the problem. Part of the problem was how to address the prevention and surveillance of hepatitis C.

We had a five-year program for $50 million per year with a 10-year commitment. It was renewed, by the way. It was due to end in the last fiscal year and was renewed again this fiscal year by Minister Pettigrew. But there is no commitment to renew it again.

In that strategy would be a communications piece, working with national partners to disseminate information to their constituents, so that the class action website isn't bombarded and the administrators aren't bombarded. You have to remember these people are living with chronic diseases, as I am. When we get concerned and stressed and don't know what's happening, it has a significant impact on our disease state; the disease progresses faster and there are other complications, and things like that.

It would be nice and sensitive of the government to disseminate information and share information with its national partners. I believe that would speak to a national strategy, as well.

● (1230)

Hon. Brenda Chamberlain: I'd like to ask the chair—or the vice-chair, or whoever—to write a letter or something to the minister on that point, the communications. I'd like consideration of that, because it is something we absolutely could get on top of and try to help this group out with a little, if that's possible.

The Vice-Chair (Mr. Rob Merrifield): All things are possible, all of a sudden.

Hon. Brenda Chamberlain: They certainly are.

The other thing is the documentation you've shown. So often I find that with my constituents on many varied issues you almost think it's there to frustrate you and make it so you can't progress and qualify, or go ahead. Perhaps you want to talk a little about that.

Mr. Scott Hemming: There's no duplication in here. These are actual applications for the 1986 to 1990 class action settlement. There is correspondence here with my lawyer, who's just a great guy and doesn't charge me anything. Thank God he doesn't, because I'd owe him a lot of money.

It has really required a lawyer, because this fund was established almost as a court. It's not a friendly process for the victims, by any means. It's a court and it's logical that you have to present burden of proof, but how much? How far do you have to go? Do you have to go to the extent of asking for anesthesiologist reports, discharge records, and things that don't exist anymore? These people are scrambling, tunneling through hospital basements looking for records that don't exist, that have disappeared. They don't keep them that long.

My fear is that if we open up the 1986 to 1990 package to everyone, especially prior to 1986, those records aren't going to be there. It was never user friendly for the 1986 to 1990 folks, but for people outside of that window it's really going to be tough to prove their infections.

Right now I think about 14% have been eliminated from the 1986.... I know individuals who in all likelihood were infected through the blood system, but they couldn't prove it enough for the administrators and the 1986 class action. They were never compensated, even though they were infected between 1986 and 1990. They couldn't prove it enough.

I'd have to say that specifically removing that sustainability piece is a key factor. Looking at some of the eligibility criteria is definitely an issue, because the way it's established now it's going to be really hard for people outside of it to establish their claims. The provincial claims are different. The Red Cross structure was entirely different and much more user friendly. They didn't have very much money in the Red Cross fund, so they couldn't spend a lot of money on proving this. In the 1986 fund they had the money, so the Canadian Blood Services spent, I think, $1.2 million a year on proving people's infections. A lot of money was spent.

The Vice-Chair (Mr. Rob Merrifield): Thank you.

Hon. Brenda Chamberlain: May I have just one comment to Charles, please?

The Vice-Chair (Mr. Rob Merrifield): Okay.

Hon. Brenda Chamberlain: I don't usually take up a lot of time on this committee; I let you guys do it all.

The Vice-Chair (Mr. Rob Merrifield): You'd better hurry.

Hon. Brenda Chamberlain: Charles, as a mother of three sons, I'm really pleased that you've been able to somehow get back with your son. That is so very important. It broke my heart to hear you say there was a time when you couldn't. I understood what you were saying and it touched me very deeply. I wanted you to know that. Thank you for your good graces.

I hardly ever say anything here, so they can at least allow me once.

Mr. Charles Duguay: Yesterday I was supposed to be at the hospital. My daughter-in-law was there to give birth to my second grandchild. She was supposed to give birth in the morning, but she delivered at 4 o'clock when I was in the airport coming here to speak to you people. Now I've got a granddaughter.

● (1235)

The Vice-Chair (Mr. Rob Merrifield): Congratulations.

Ms. Demers.

[*Translation*]

Ms. Nicole Demers: Thank you, Mr. Chairman.

Mr. Hemming, you seem pleased when people ask you questions. If you don't have an answer, I'm confident Ms. Tough can supply one. Do you know if the fund sets out a payment schedule for lawyers similar to the one in place for victims? If it does, how much money has been spent thus far on legal fees? Furthermore, how much money has been spent on legal fees in connection with the class action suit filed?

[*English*]

Mr. Scott Hemming: The amount paid for the class action lawyers between 1986 and 1995 was $50 million—in that sum. For the victims outside of that, an amount hasn't been determined to date by the class action lawyers who have brought that before the courts.

[*Translation*]

Ms. Nicole Demers: Thank you.

Ms. Tough, a total of $6 million was spent last year to administer the fund. How was this money spent? How many people are involved in managing the fund? What expenses were posted? Six million seems like a great deal of money to me, even if it represents only 10 per cent of all fund disbursements last year. It was my understanding that only $100 million of the $1 billion set aside to compensate victims had in fact been paid out. Is that in fact the overall amount of money that has been spent since the fund was created? The largest amount was paid out last year. Since the fund was set up — I believe the year was 1998 — and up until the present day, only $100 million has been spent. Therefore, every year, approximately 10 per cent of the fund's assets are used to cover administrative costs. That seems like a great deal of money to me.

[*English*]

Ms. Bonnie Tough: Let me respond. The total amount paid to victims in the 1986 to 1990 group from inception was approximately $400 million. Mr. Hemming and I have had our debates over the years, but let me comment on a couple of things in terms of the administration of the fund.

First of all, the burden of proof is not on the claimants. There are procedures in place to try to ensure that the compensation is paid to persons who were infected with hepatitis C by blood between 1986 and 1990. That of necessity involves some review, but we have put in place procedures to try to assist claimants. For example, Mr. Hemming, or perhaps Mr. Rice, talked about the difficulty in obtaining medical records. It is very difficult. Doctors move, hospitals close—it has been a nightmare.

Initially, a claimant is asked to produce their medical records. If they cannot produce those records, the fund does not say no, go away, you can't produce your records. The fund then has nurse claims officers in place who liaise with the hospitals, work with the hospitals, and work with the professionals to try to find the medical evidence. They go back to the blood banks in the hospitals, check the records, and see if they can find proof of the transfusion. That's the first step, and it is a very labour-intensive, time-consuming step.

As for the cost of the administration of the fund, one of the costs has been in what's called trace-backs. You get the blood records and they indicate that someone has had 10 transfusions. Those transfusion records are given to the Canadian Blood System to analyze and trace back. They come back and say all of those transfusions were negative for hepatitis C; one of those transfusions is positive for hepatitis C; or some of them we can't trace. If they're positive, or if they can't trace them, it's inconclusive, they become a class member.

So the system is tilted in favour of the claimant, but it does take time. We discovered at the very beginning that we were bogged down with these trace-backs in CBS. CBS did not have the people to do them in a timely fashion. With the permission of the courts, we took several million dollars and transferred it to CBS to hire staff to do these trace-backs so the claimants could get paid.

The people who are involved in this, certainly from the lawyers' and the joint committee's standpoint, are people who are interested in getting claimants proper compensation. We have a problem in this country, though, because—and I don't have the exact numbers with me—we have literally tens of thousands of people who each have two things: one, they had a blood transfusion; and two, they have hepatitis C but the hepatitis C did not come from the blood transfusion. We cannot compensate just on the basis that someone is infected with hepatitis C, because as the number was given earlier, there are 250,000 people in this country with hepatitis C. We have to have some way of trying to locate and ascertain the victims who were tainted by blood in the 1986 to 1990 period.

The staff at the centre in Ottawa have been cut back as they have become more experienced. As the need for trace-backs has diminished, we've cut back on the staff, and we've cut back on their budget. The administration has become cheaper over time—as you would expect—as they handle the claims, but they are told to assist people; they are told not to operate like a disability insurance plan. The idea is to get everyone possible who meets the criteria into the tent, and that's what we're trying to do. It costs money, and it costs a lot of money. It costs money not only for claims officers, but for lawyers as well. We have a complete right of appeal. If someone is refused, they can appeal. We have arbitrators and referees across this country, and people can go before them. Lawyers as well are involved in those appeals.

● (1240)

The job of the so-called fund council is to protect the fund, to make sure that eligible claimants receive money, and that claimants who are not eligible do not. It is tremendously complicated. This is the most complicated and largest class action settlement in this country. It is expensive, there's no question about it. But we also have $400 million paid to, if you count family members, almost 10,000 people.

So yes, some are probably unhappy, but I think a large number of people have been very well served by it.

The Chair: Thank you, Madame Demers.

Mr. Thibault, followed by Mr. Goodyear.

Hon. Robert Thibault: *Merci beaucoup, madame la présidente.*

Hopefully, I'll get a chance to get a question in, but first, I'm glad we made that point about the trust. You can always sensationalize things by talking about the empirical, about the money for administration, but if you look at similar types of things, such as mutual funds, there are legal fees, brokerage fees, administrative fees, accounting fees, auditing fees. All those apply also to these trusts. It is money that is put in trust for the trustees. Those become necessary, and I'm glad madame had a chance to point that out.

I think we all agree on the compensation. We're going forward there. I want to assure Scott that, to my understanding, it's not the existing fund or nothing, or that the section necessarily has to be changed. I think when the minister says “reviewing options”, he means reviewing options. All options are on the table.

What I'd like to talk about a bit—Scott and Jeff, you alluded to it—is the question of where we go from here. The three afflicted people here made good presentations. I'm at risk as well, from another blood disease; I had to get cryoprecipitate when I had dental work done in the past. I was lucky, as opposed to you, because I didn't get infected, but I was also one of those at risk.

Outside the blood system, which we're talking about, I believe 2,500 a year become infected with blood-borne diseases—

● (1245)

Mr. Jeff Rice: It's 5,000.

Hon. Robert Thibault: It's 5,000 a year? So that's something we also have to work on.

You were also talking about specific disease funding. We get that all the time, or I get that all the time, in presentations from people on prostate surgery or diabetes or heart disease or cancer. They're all asking for specific funding from the department, but all agree with the comprehensive approach. They all agree with the comprehensive approach, but they don't want to have to argue for their funds again.

I'd like you to speak to that point and also to what both of your organizations do to try to work with other organizations, including governments, to try to lessen the amount of infection yearly.

Mr. Scott Hemming: From our perspective, we've been rather limited in our capacity to respond, because we don't have any federal funding. We have a contribution agreement with the Ontario government, and we raise money through fundraising. Other than that, we have one staff person right now, our executive director, who's probably on the phone answering many questions from people who are concerned.

To be honest, we've done some great initiatives over the years to stop the spread of hepatitis C. Jeff mentioned the strategy document, which was a collaboration of organizations, including the Hepatitis C Society of Canada, the Canadian Liver Foundation, and many others. It was a very broad-based collaboration. It's a rationale for a strategy, and I think that strategy is something that will work in the future to prevent future infections.

I think HIV/AIDS estimates are at approximately 5,000. We estimate approximately 5,000 to 10,000 in hepatitis C, because hepatitis C, through IV drug use, is more contagious than HIV. We estimate about 10,000. So we're looking at about 15,000 through blood-borne pathogens and infections every year. That's quite a significant number. When we have 250,000 people out there with the disease, and only one-third of them have been diagnosed, that's a huge number of people who can go out and transmit the disease, not knowingly, to others, even inside their family, through toothbrushes or a variety of other things.

So encouraging people to be tested, if they have any risk factors, is a dialogue we've had—with the provinces, in terms of establishing provincial campaigns, and at a national level, with the program people as well.

Jeff, do you have anything to add?

Mr. Jeff Rice: I think I would just encourage people to review the document we developed together, as a coalition of community groups. It outlines what needs to be done.

The program that was introduced was really a bit of a knee-jerk reaction to a political situation. I don't think it was really well thought out. I think this is the community's proposal to creating a strategy. There's a certain degree of permanence or seriousness around a strategy as opposed to just a program.

The Chair: Thank you, Mr. Thibault.

Mr. Goodyear.

Mr. Gary Goodyear (Cambridge, CPC): Thank you.

I would like a clarification on some of this funding. It was mentioned earlier, I think by Ms. Tough, that $400 million has been paid out to victims since the inception of this fund.

Can you tell me how much has gone out in non-victim costs? How much has gone out to accountants and arbitrators, or to setting up and operating this fund?

Ms. Bonnie Tough: I don't have that number, but as I indicated, I think it was about 10% last year. I think it's been within that range.

Mr. Gary Goodyear: But that's just an operational cost—

Ms. Bonnie Tough: The 10% includes, as I said, all of the costs incurred by the fund, from the investment mangers to the auditors to the lawyers to the trust managers to the—

Mr. Gary Goodyear: It almost sounds like a job creation program here, with all these people involved.

Ms. Bonnie Tough: It is a complicated fund. It is a trust fund, held by a trust company, managed by professional advisers, audited by a major accounting firm, and reviewed by the courts in three provinces. Yes, it does occupy people's time.

Mr. Gary Goodyear: The figure I have in front of me shows $250,000 a month going to Crawford in Toronto alone.

Ms. Bonnie Tough: Well, Crawford is not in Toronto, Crawford is in Ottawa, or the operation of the centre is run through Ottawa. I can't recall their monthly budget, but they run the fund, and it would not surprise me that it's in that range.

● (1250)

Mr. Gary Goodyear: Would it be surprising if the figure was $200 million to non-victims, since inception, to get this thing up and running?

Ms. Bonnie Tough: You are including in that number the class counsel fee—

Mr. Gary Goodyear: Yes.

Ms. Bonnie Tough: —which had nothing to do with the running of the fund as opposed to the establishing of the fund?

Mr. Gary Goodyear: Right.

Ms. Bonnie Tough: No, that wouldn't surprise me, if you're including those fees.

Mr. Gary Goodyear: So really, it's 50%, not 10%.

Ms. Bonnie Tough: You are not being fair to the figures.

Mr. Gary Goodyear: Okay, well, let me be fair to the figures and ask if GST is charged to all those figures.

Ms. Bonnie Tough: If GST is charged to all those figures?

Mr. Gary Goodyear: Is the federal government collecting GST on those figures?

Ms. Bonnie Tough: Some payments are subject to GST, and some payments are not.

Mr. Gary Goodyear: Okay.

To Mr. Hemming, it seems to me we've missed the point on this. The point is not whether there is, or will be, enough money in this fund. The point is one of responsibility. The government has a responsibility to these victims. It seems to me that waiting to see whether there's enough in the fund is skirting the real issue, and that's accepting responsibility, funding these individuals, as they should, now. If there's not enough money, then we have to come up with that.

How would you comment on that?

Mr. Scott Hemming: I'd come back to the level of cooperation I saw with all political parties on this particular issue. The debates were fantastic in the House of Commons. That was one of the first times there wasn't a political mishmash back and forth. Everybody was agreeing to get things done.

You're absolutely right about what the point is here: let's get this done. As to what is the quickest mechanism to do that, I don't really have the answer. I am speaking to a particular section in the agreement itself, section 4.02, that outlines the federal, provincial, and territorial governments' lack of liability for the fund in the future, putting the onus on the victims. What I'm saying is that if we remove that part, the courts would probably be more likely to.... Well, I don't think an actuarial study would be necessary.

Bonnie could probably speak to that better than I could, but that's something I would explore.

As well, as I think the Honourable Mr. Thibault asked us, are there other ways, as the minister said, to possibly look at this? One thing that struck me is that we could mirror the 1986 to 1990 package. All of the paperwork's done. Everything's done. It would require a commitment by the federal government for some new money now, but as Ms. Tough mentioned, the court has the right, at the end of the actuarial study, to give that money back to the federal, provincial, and territorial governments. It then could be run by the government itself, as the HIV plan is, and be much more friendly, without mounds of paper for the victims.

So there are other options, and I'm glad Mr. Thibault mentioned that. I really believe the accountability should be on government on this, and not so much on the private sector. The freedom of information acts are not there; you can't get information. On the audited financial statements, we don't know exactly what the legal fees are per person, or what the accountants are charging. We just have a broad amount.

I think a government-run program may be much more friendly for the victims, and certainly they could turn to their members of Parliament to get assistance. I know members of Parliament are always quick to help.

The Chair: I think Ms. Tough would like to respond to that as well.

Ms. Bonnie Tough: Can I make a comment? On the disclosure of moneys, I don't agree with the $200 million figure that was just put before the committee. The costs are much lower than that.

In any event, the costs are completely public, and are filed with the courts every year. No one who has received money from this fund other than claimants has not had to file their accounts with the courts, in one or all of the three provinces, and have them approved. If you go on the website, and you go to the annual report, you can see a breakdown of where the moneys have been spent—how much has been spent for Crawford, how much has been spent on investment advisers, how much has been spent on lawyers.

There's no secret here. And as I say, the number is nowhere near the $200 million, even if one includes the class counsel fees, which I would question.

● (1255)

The Chair: Thank you, Mr. Goodyear.

Mr. Thibault.

Hon. Robert Thibault: No, that's fine.

The Chair: On behalf of the members of the committee, I will thank very much those people who gave of their time and energy to come here and share their thoughts on this topic. You've been most helpful. We will take these pieces of information forward as we continue to work as a committee on your cause. Thank you very much.

I have one announcement for members of the committee. We can't get the room for next Tuesday's meeting at our regular time in the afternoon, so it will be held at our Thursday time, which is 11 a.m. until 1 p.m.

Ms. Ruby Dhalla: Madam Chair, the House apparently is going to be rising, possibly on Tuesday. Would we be meeting on Thursday then?

The Chair: We have no official word other than the parliamentary calendar, which says that the House rises on Friday. We are planning to meet on Tuesday.

Thank you. This meeting is adjourned.

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