

From Compensation to Reparations:  
Viewing Tainted Blood Recipients as Victims of Cultural Injustice

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*We should put a wash basin up here because all the agencies essentially come up here and essentially wash their hands of their own responsibility for what occurred.*

- James Kreppner, a hemophiliac who contracted HIV through the blood system, speaking before the Commission of Inquiry on the Blood System in Canada, March 21, 1994

## **Introduction**

A flurry of cases has dominated the news in recent years linked to damages for “medical misadventure.” The current buzzword in health law, “medical misadventure” refers to instances in which “personal injury results from the competent treatment of a disease.” (Hoey, 1998). In Ontario, victims of last year’s outbreak of West Nile virus filed a class action suit against the Ontario government for failing to protect them from the virus. Patients at Sunnybrook Hospital in Toronto discovered that they may have been exposed to infection after being examined with unsterilized equipment. In major U.S. cities, there is a growing movement of claims linking increased rates of asthma in children to environmental factors such as diesel exhaust. (Brown et al 2003).

One of the most high profile and scandalous cases of “medical misadventure” involved the contamination of thousands of Canadians during the 1980s with HIV and Hepatitis C. The case dominated national and international headlines for several years as victims appeared before a public inquiry to recount their personal narratives, while many of the individuals who ran the blood system explained that this was an unavoidable tragedy, that officials made the best use of the limited information they had at the time. Governments responded to the public outcry over the damning details of this case by offering in 1989 compensation packages first to the 1,100 Canadians who contracted HIV and later in 1998 to thousands of others who contracted Hepatitis C. A particularly heated

debate took place during that year over whether the government's decision to compensate those infected with Hepatitis C between 1986-1990, when the government acknowledged its responsibility for failing to implement blood testing, but not those infected before 1986 and after 1990. The compensation package for people infected with HIV, the majority of them hemophiliacs, had no cutoff periods, perhaps due to the smaller number of potential claimants.

While there has been some discussion of the legal issues surrounding compensation for blood injury, including a lengthy treatment of the benefits of no fault compensation schemes in Justice Krever's three-volume final report on the tragedy, there has been almost no discussion on how tainted blood compensation might relate to cases of reparations for historical injustices, ranging from claims made on behalf of victims of slavery to Aboriginals in residential schools to Chinese-Canadians who had to endure the "head tax". This paper asks whether people with hemophilia who contracted HIV and/or Hepatitis C through the blood system should also be viewed as victims of cultural injustice. The dominant approach to understanding the claims made on behalf of tainted blood recipients has been the narrow frame of compensation for medical injury. Blood recipients, it is argued, were the unwitting victims of a system that placed a premium on cost-savings over patient safety. They were not singled out because of their membership in a particular community. During the public inquiry into the tainted blood scandal, however, witnesses testified that they felt singled out as a 'disposable population' who, by virtue of their reliance on blood or blood products, were quite likely already infected anyway. Giving contaminated blood to members of a community who were presumed to be already infected made sound economic sense. Hemophiliacs were the quintessential

“canaries in the mine shaft,” who died in order to signal to others the dangers present in our blood supply.<sup>1</sup> As members of a tight-knit community who often refer to each other as ‘blood brothers’ (hemophilia almost always affects men), people with hemophilia have been stigmatized and subjected to schoolyard taunts from classmates who viewed them as sissies because they had special medical needs.

This paper argues that the inarticulation of recognition claims to remedy cultural injustice simplified the state’s response to those people with hemophilia who became infected. The first section of the paper provides a brief overview of the compensation debate surrounding tainted blood in Canada, paying particular attention to the distinction between people infected with HIV and those infected with Hepatitis C. Some hemophiliacs, it should be stressed, were doubly infected with HIV and Hepatitis C. This poses some unique treatment problems as HIV has been shown to accelerate the course of chronic liver disease and in some cases Hepatitis infection may worsen the prognosis of HIV. The second section reviews some of the current literature on reparations politics, and asks how the tainted blood case might figure in or fit into this analytical framework. The third section sketches the contours of an argument for viewing people with hemophilia as victims of cultural injustice, arguing that this “community of suffering” transformed itself into a powerful political force despite the stigma associated with this condition. To make this argument about the distinctiveness of hemophilia culture, however, should not be construed as diminishing somehow the claims made by others (non hemophiliacs) infected with tainted blood

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<sup>1</sup> Susan Resnik, *Blood Saga: Hemophilia, AIDS, and the Survival of a Community*, Berkeley, Los Angeles, London: University of California Press, 1999, p. 2.

## **Compensating the Blood Injured: Some Victims are More Deserving than Others**

The issues surrounding compensation for receiving HIV-tainted blood went largely unnoticed in the popular press, in contrast to the very public battles which would ensue over Hepatitis C compensation. And, for the most part, those infected with HIV-tainted blood, the majority of them hemophiliacs, were quite content to keep it that way. In 1989, the federal government, which had rejected the idea of assistance for fear that it might imply wrongdoing, quietly acknowledged its role in contaminating the blood supply with HIV. Health Minister Perrin Beatty announced the terms of a carefully worded Extraordinary Assistance Plan (\$30,000 a year for four years) as compensation for inflicted harm. The decision came only six months after one of the largest gatherings of AIDS researchers in the world, the International Conference on AIDS, which was held in Montreal in June 1989. At the meeting, Prime Minister Brian Mulroney first spoke publicly about AIDS:

Having this illness neither diminishes people's humanity nor limits their rights. People are entitled to our respect as well as to our compassion. Shunning people with AIDS or attaching stigmas to the illness obscures the existence of AIDS when precisely the opposite is required... It is morally offensive, at the very least, to make persons with AIDS the outcasts of the twentieth century. It is also inhuman, the sort of blind ignorance which should make us thoroughly ashamed.<sup>2</sup>

During the late 1980s, there was little discussion of the wisdom of offering only a four-year package to tainted-blood recipients infected with HIV. This was partly due to the fact that it was presumed, given the limited scientific knowledge at the time, that the recipients would succumb to AIDS in a relatively short time, as was the case with other people with AIDS. Much to the surprise of the federal government, however, the majority of those infected (655 out of a total of 976) were still alive four years later as the package

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<sup>2</sup> Mulroney, quoted in André Picard, *The Gift of Death*, op. cit., p. 169.

was set to expire. At that point, Janet Connors, then a little known wife of a Nova Scotia hemophiliac, began pressuring that province's health minister to pick up where the federal government package had left off. After several meetings with Connors and her husband Randy, Nova Scotia Health Minister George Moody promised to try his best, but his appeals to his provincial and territorial counterparts, to reopen the compensation issue were unsuccessful. By April of 1992, Moody finally persuaded his province to go it alone. The Minister's decision, coupled with mounting pressure from tainted-blood recipients, eventually pushed the provinces and territories to reverse their original decision. On September 15, 1993, a day before the Commission of Inquiry on the Blood System in Canada was to be formally announced, the details were made public of the Multi-Provincial-Territorial Assistance Program for people who acquired HIV through the blood system. Persons infected with HIV between 1978 and 1989 would receive a \$22,000 bonus for signing on to the plan, plus \$30,000 annually for life. Survivor benefits included \$20,000 per year for a spouse and \$4,000 per child for five years. But there was an important catch: the deadline to accept or reject the package was March 15, 1994; many speculated that this deadline was set to "force victims to decide if the program was adequate before there was a judgment issued in a civil suit and, more important, before Mr. Justice Horace Krever (the head of the public inquiry) could make any recommendations."<sup>3</sup> In addition, the deal required that "victims" sign a waiver releasing the provinces, territories, the Canadian Red Cross Society, the Canadian Blood Agency, blood product manufacturers, hospitals, physicians, and their insurers of any liability. Against their better judgment, many chose to accept the deal since it meant short-term financial relief and the avoidance of lengthy, costly legal battles in court. As one victim

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<sup>3</sup> André Picard, *The Gift of Death*, 1998, op. cit., p. 176.

testifying before the Inquiry said of the package: “I really question why it is called assistance when a seventeen-page waiver is required.”<sup>4</sup>

While their predecessors were able to win compensation for all recipients of HIV-tainted blood regardless of the date of infection, people with Hepatitis would not be so fortunate. With the help of information released at the Inquiry, and supplemented by their own amateur sleuthing, activists worked tirelessly to uncover evidence to substantiate their claim that the cut-off period was an arbitrary one. ALT testing, they would argue, was available much earlier. In West Germany, for instance, the test, which measures the likelihood of liver dysfunction, was implemented as early as 1968.

The Hepatitis compensation issue reached its peak during the spring of 1998 following the announcement on March 27 of a limited compensation package offered by the federal, provincial and territorial governments. What made the issue of Hepatitis C so contentious, as far as possible government compensation was concerned, was the presumed lack of scientific knowledge of the disease<sup>5</sup>, not to mention the sheer variation in the number of people possibly eligible for compensation. (The initial number of people infected with Hepatitis C was estimated at 60,000, compared with about 2,000 infected with HIV.) Until 1989, Hepatitis C was known only by what it was not (non-A, non-B Hepatitis). Much of the debate centered on the wisdom of compensating a group of people whom, it was argued, were not faced with a disease as life-threatening as AIDS. In an ironic turn of events, however, thanks to the development of “drug cocktails”, some

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<sup>4</sup> Testimony of Mr. and Mrs. Z at the *Commission of Inquiry on the Blood System in Canada*, Vol. 15A, Toronto, March 11, 1994. Quoted in Picard, *The Gift of Death*, 1995, op. cit., p. 236.

<sup>5</sup> One senior government bureaucrat, who spoke on condition of anonymity, noted in an interview that studies commissioned by the government even called into question the validity of the symptoms – such as extreme fatigue – experienced by people with Hepatitis C. The bureaucrat also added that the bulk of tainted-blood recipients were interested primarily in money, not in seeing that Hepatitis C be taken seriously by government as a public health issue.

of the same people infected with HIV in the 1980s are living longer, productive lives than people infected with Hepatitis C, heretofore regarded as a less-serious, non-life threatening disease.

During its peak in the spring of 1998, the Hepatitis C story led national television newscasts and dominated radio call-in programs. Prime Minister Jean Chrétien, who was visiting Cuba during the time, was summoned back to Ottawa to ensure that the party faithful voted with their government on this issue. Allan Rock, the Minister of Health, became the media's favorite whipping boy. On the day reserved for discussion of Hepatitis C in the House of Commons, Rock appeared indignant in his belief that the deal he was instrumental in striking with the provinces and the territories was the best solution to a dilemma with possibly far-reaching implications for the Canadian health-care system. Commenting on the problems inherent in extending compensation to all, Rock said:

The true question is whether governments should make cash payments to those who are harmed through no fault of anyone but because of risk inherent in the medical system...

The easy course, naturally, would be simply to pay those who are making a claim upon the government. Ministers of Health are custodians of Canada's health care system and we have a larger responsibility, a responsibility to show leadership on these tough questions and confront them directly, no matter how difficult they may be...

The moral high ground does not rest with those who urge that easy course. The true moral high ground is with those on this side of the House with the courage to stand and say we will take the tough decision on the difficult question we face. The true moral high ground rests with those in the government who will stand in their places next Tuesday and vote against this motion not because we are callous, not because we lack compassion, but because we are responsible for a public health care system that cannot and will not continue if we take the course the opposition urges.

Can we sustain our public health care system if we make cash payments to all those who are harmed by the health care system, regardless of fault, merely because of the risk inherent in the process?



Infection with hepatitis C through the blood system was just such an inherent risk before January 1986. As a result I say we should conduct research, we should do whatever we can to prevent such injury in the future, we should accept responsibility for the period when we should have acted, but I oppose this motion because it is not the proper policy.<sup>6</sup>

Grant Hill, the medical doctor who spearheaded the then Reform Party's campaign to extend compensation, tried to refute the rationales upon which the government decision was based. The first rationale – the 1986-1990 timeframe – was “an arbitrary legal dividing point... It is very evident that the regulators messed up; Judge Krever said so plainly and clearly. The special new test the government said was unavailable before 1986 was developed in 1958. I have practised medicine in this country and I have used that test for much of my medical career.”<sup>7</sup> The second rationale, that extending compensation to all people infected with Hepatitis C through the blood system would set a dangerous legal precedent, is wildly exaggerated. “The health minister went on to say that other medical misadventures like breast implants or obstetrical tragedies would be under the same cloak if we were to compensate all victims of Hepatitis C. That is wrong. If I made a medical mistake, I would personally be sued for that mistake... If a manufacturer were to make faulty medical devices, it would be sued.”<sup>8</sup> The third rationale (since all governments agreed to the deal, it must be right) neglects the fact that all governments – federal, provincial, and territorial – are implicated in this tragedy. “Krever has said that the provinces as well as the federal government are responsible.

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<sup>6</sup> *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998. Available electronically at: [http://www.parl.gc.ca/36/1/parlbus/chambus/house/debates/091\\_1998-04-23/HAN091-E.htm#LINK115](http://www.parl.gc.ca/36/1/parlbus/chambus/house/debates/091_1998-04-23/HAN091-E.htm#LINK115)

<sup>7</sup> *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998.

<sup>8</sup> *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998.

The federal government takes the brunt of this responsibility sadly, but just because 13 people rob a bank, does that mean robbing a bank is right?”<sup>9</sup>

Soon after the federal government released the terms of the limited compensation deal in 1998, Ontario Premier Mike Harris broke ranks and announced that his government would agree to compensate those Hepatitis C patients shut out of the package. Condemned by Chretien’s Liberal government as a calculated political move, the decision nonetheless pleased some activists. In the following summer of 1999, federal, provincial, and territorial governments and legal counsel for Hepatitis C claimants filed a proposed settlement agreement with the courts for final approval. As it sought to settle class-action lawsuits launched in Ontario, British Columbia, and Quebec, the courts in these provinces had to approve the deal. It was later revealed that class-action lawyers across Canada who negotiated the compensation deal earned \$52.5 million for their efforts.

In the fall of 1999, people with Hepatitis C who were shut out of the \$1.1 billion deal took their fight to Washington, D.C., arguing that Canada knowingly accepted prison plasma from Arkansas and Louisiana in the early 1980s, and was aware of the fact that the plasma was contaminated with Hepatitis C and/or HIV. The lawsuit named a Toronto pharmaceutical company (Connaught Laboratories Ltd.) that manufactured blood products until 1987, a blood broker that bought plasma from the U.S., and the Bureau of Biologics of Health Canada, which monitored the safety of the blood supply. Others implicated include then-governor of Arkansas, Bill Clinton, who allegedly had links to a

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<sup>9</sup> *Hansard*, debate in the House of Commons on Hepatitis C compensation, April 23, 1998. Extending the analogy, CTV reporter Craig Oliver commented on the relationship between the federal government and the provinces vis-à-vis tainted blood, noting: “If Ottawa was robbing the bank, the provinces were driving the getaway car.”

U.S. firm that collected the prison blood, and Paul Martin, who during the 1980s sat on the Board of Directors of Canada Development Corp., of which Connaught was a subsidiary.<sup>10</sup>

Finally, in April 2000, as activists had feared, the courts in the three provinces approved the deal, which clearly spelled out that the governments, in settling the action, “do not admit any liability or wrongdoing on their part.” The settlement funds are to be distributed based upon severity of illness, from Level 1 (a fixed \$10,000 plus reimbursement of some medical-related expenses) to Level 6 (up to \$225,000 for persons with advanced stage liver disease attributable to HCV infection).

The federal government’s decision in December 1989 to compensate hemophiliacs who had contracted HIV via tainted blood, but not countless others who contracted Hepatitis C, helped to create a hierarchy of victimhood.<sup>11</sup> Indeed, the public inquiry also played a role in problematizing the notion of “victim”. As the process unfolded, sharp differences emerged over who could legitimately claim the “victim” label. People who acquired Hepatitis C through the blood system were criticized for embracing the role of innocent victim, since the qualifier “innocent” seemed to suggest that others with Hepatitis C or HIV who were not infected through the blood system were somehow to blame for their condition. However, the “innocent victim” label was espoused not only by people with Hepatitis C. Hemophiliacs who were infected with HIV also portrayed themselves as victims of government neglect and corporate greed, arguing that the system in which they placed their faith and trust had poisoned them. The message

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<sup>10</sup> Mark MacKinnon, “Martin on hot seat for missing documents,” *The Globe and Mail*, April 6, 2000, p. A6.

<sup>11</sup> The final Krever Report urged governments to compensate all recipients of tainted blood, regardless of the type of infection.

that this sent to HIV-positive members of the gay community associated with the AIDS movement, was that there was an important line separating those who had engaged in “careless” activities (sexual or drug-related) that carried the risk of HIV infection, from others who had mistakenly trusted a system that was supposed to look after their needs. Moreover, tension between the AIDS community and the tainted blood community was further fuelled by suggestions that “careless” members of the AIDS community were actually responsible for the contamination of the blood supply in the first place.

In effect, tainted-blood recipients were implicitly classified according to the way in which they were infected (transfusions, use of blood products) and the type of infection (HIV, Hepatitis C or, in some cases, both). At the inquiry, there were representatives for people who contracted Hepatitis C (Hepatitis C Society of Canada), for people with hemophilia (the Canadian Hemophilia Society), and for those who contracted HIV through transfusion (the HIV-T Group). Those who were infected after receiving transfusions of blood components (red cells, platelets, or plasma), usually in the hospital and often in the course of surgery, are referred to as occasional users of the blood system. In contrast, hemophiliacs who use factor concentrates (blood products that are used to treat hemophilia) are considered frequent users of the blood system. Severe hemophiliacs depend on these products to treat their frequent bleeding episodes. In 1985, blood system officials had developed “triage criteria” to deal with the problem of having separate stocks of factor VIII concentrate that were heat treated and not heat treated. Heat-treated factor concentrates were “heated” to kill viruses and bacteria in a manner similar to the pasteurization of milk. According to one account, it was agreed that: “Heat-treated factor VIII concentrate would first be reserved for hemophiliacs who had never

been exposed to untreated blood products; next, it would be made available to hemophiliacs who had been treated least with such products or had received only cryoprecipitate. Young hemophiliacs would receive priority.”<sup>12</sup> This “Schindler’s List”, as some hemophiliacs referred to the triage program, was not needed, however, as “only one million of the 15 million units the CRCS (Canadian Red Cross Society) received at the time were ever distributed, presumably in an effort to use stocks of untreated material that otherwise would have had to be recalled and destroyed.”<sup>13</sup>

### **Blood and Money: Toward a Reparations Perspective?**

What is the link between tainted blood and other instances of cultural injustice in which claimants have demanded reparations? What is the purpose of thinking through this case using a reparations lens? Of course, given that reparations by definition involves some form of material compensation (usually of a monetary nature), one might immediately view tainted blood compensation as an attempt by the state to repair the injustice dealt to these citizens. Indeed, the title of the paper may appear confusing given that compensation is identified as one form of reparation. (The other two are restitution and “truth telling and apology.”)<sup>14</sup> I argue, however, that the compensation scheme devised to deal with tainted blood claimants was narrowly concerned with cleaning up a political mess, “concerned with delivering the goods, rather than the good.”<sup>15</sup> In other words, it was compensation narrowly defined. In addition, I suggest that the process

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<sup>12</sup> Norbert Gilmore and Margaret A. Somerville, “From Trust to Tragedy: HIV/AIDS and the Canadian Blood System,” p. 139, in Eric Feldman and Ronald Bayer (eds.), *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*. New York, Oxford: Oxford University Press, 1999.

<sup>13</sup> Norbert Gilmore and Margaret A. Somerville, “From Trust to Tragedy...” p. 139, in *Blood Feuds*, op. cit.

<sup>14</sup> See Debra Satz, “Reparations and International Injustices: On the Limits of the Compensation Paradigm,” paper presented at Reparations Conference, Queen’s University, Feb. 2004.

<sup>15</sup> Catherine Lu, “Reparations Beyond Borders: Of Debt and Disgrace after War,” paper presented at Reparations Conference, Queen’s University, Feb. 2004, p. 4.

through which claims were made against the state for compensation neglected a potentially powerful argument regarding the cultural harm that was inflicted on people with hemophilia as members of an identifiable group. Indeed there is a bias in the reparations literature toward the study of remedying cultural injustice, which does not easily accommodate those instances which involve medical as well as cultural injury.

Although reparations normally refers to “monetary or material payments made by the state and/or offending parties to victims of acknowledged moral transgression,”<sup>16</sup> I argue that the compensation offered to tainted blood recipients was less concerned with repairing the past than it was with avoiding potentially costly legal liability in the future. In addition, although governments and blood system officials outside of government apologized for the failure to adequately protect the blood supply, this was far from any admission of moral wrongdoing. According to Lu, “material transfers” may only be termed restitution or compensation “when made in response to an acknowledged moral wrong.”<sup>17</sup>

While the act of offering compensation tackled the thorny issue of redistribution, it did little to satisfy the increasingly acrimonious battles over representation and recognition, battles which were unconsciously condoned by the inquiry charged to examine the scandal. Victims not only demanded money and the criminal prosecution of those individuals who may have had a hand in their infection<sup>18</sup>; they wanted assurances

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<sup>16</sup> Catherine Lu, “Reparations Beyond Borders,” p. 4.

<sup>17</sup> Catherine Lu, “Reparations Beyond Borders,” p. 4.

<sup>18</sup> Justice Krever’s Final Report was publicly criticized for failing to directly point fingers at individuals and institutions, this despite the fact that Krever fought and won the right to make allegations of misconduct. In its unanimous decision, the Supreme Court of Canada warned that he must be careful in his wording so as not to impute any criminal culpability or civil liability to those named. The reason for this restriction is that the rules of evidence at an inquiry are markedly different from the rules of evidence in a court of law. Notably, inquiry witnesses have the right to not incriminate themselves by refusing to testify, nor do their counsels have the right to cross-examine witnesses thoroughly. To have allowed Justice Krever

that their voices would be heard and/or represented. As one official from the Canadian Hemophilia Society said: “They’re (the parents are) living with the idea that they gave their kid the shot that killed him. They need to hear an admission.” While recognizing the importance of representation, and reserving space for victims to recount their painful narratives, the Inquiry did not, as Nancy Fraser argues in her essay on the “recognition-redistribution dilemma”, transform group identities. Rather, it affirmed or encouraged group differentiation. For instance, the discourse surrounding the issue of compensation distinguished the deserving from the undeserving, and pitted hemophiliacs who contracted HIV against others who contracted Hepatitis C and against those who did not contract HIV through the blood supply, such as intravenous drug users.

Torpey’s attempt to map reparations claims, while useful in some respects, seems to leave little room to consider cases such as tainted blood. In his figure, the east-west axis, which covers the symbolic and economic, and the north-south axis, which covers the cultural and legal nature of reparations claims, certainly encompass a range of possible cases, from residential schools (symbolic) to slavery and segregation (economic). The closest link to the case in question is found in Torpey’s discussion of symbolic reparations, in which he includes “comfort women” and Japanese persons interned during WWII. As he explains, these types of claims “are not generally justified in terms of any alleged cultural destruction but in terms of the direct damage sustained by the victim. The harms for which compensation are sought are chiefly psychological rather than physical, although of course physical injuries may underlie the claims as well. The

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to suggest criminal actions or civil actions, therefore, would have breached the right to a fair trial guaranteed under the Canadian Charter of Rights and Freedoms.

main point is that the harms in question were carried out directly on the bodies of the persons to be compensated, rather than their descendants or heirs.”<sup>19</sup>

It is worth noting, as well, that while the term reparations has been used widely to refer to an ever expanding catalogue of cases of historical injustice, it has rarely been invoked when dealing with instances of medical injury. One important exception was the infamous Tuskegee Experiments in the U.S. From 1932 through 1972, the U.S. Public Health Service allowed more than 400 black men to go untreated for syphilis after offering them free medical care. The men never knew they were part of the Tuskegee Study of Untreated Syphilis in the Negro Male, nor were they aware that they had syphilis. Treatment for syphilis, initially a combination of mercury and arsenic and later penicillin shots, was also withheld from the patients. The men received treatment only when news of the secret experiments became public. By that time, 28 men had died of syphilis, 100 others were dead of related complications, and 40 wives of the men and 19 newborns had become infected. The government a few years later paid the survivors and relatives \$10 million for damages but a formal apology was only issued in 1997 by then President Bill Clinton.<sup>20</sup> This is a relevant case because it demonstrates how the cultural can mingle with the medical. In this case, there is no doubt that these men were singled out because of their membership in a racial group

Given the diversity of reparations claims made against states and other actors, it is worth examining what constitutes successful reparations claims. And, conversely, what factors may inhibit the success of reparations claimants? In an interesting discussion, reparations scholar Roy Brooks identified four elements of a successful theory of redress:

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<sup>19</sup> John Torpey, “Introduction,” p. 12, in John Torpey (ed.), *Politics and the Past: On Repairing Historical Injustices*, Lanham, MD: Rowman and Littlefield, 2003.

<sup>20</sup> Nancy Mathis, “On behalf of nation, an apology” *Houston Chronicle*, May 16, 1997.



demands must be made to elected officials whom, he claims, have more power than judges; the existence of political pressure; strong internal support; and a “meritorious” claim.<sup>21</sup>

Regarding the first element, it seems incorrect to suggest that an appeal to the courts would not be as advantageous to reparations claimants as an appeal to legislators. In the tainted blood case, it is generally accepted that key claims brought by victims before the courts spurred governments to respond swiftly lest they be exposed to wider civil liability. The second element, political pressure, is critical, he notes, because it helps to explain why some meritorious claims fall flat while other, perhaps less meritorious claims, are dealt with successfully. What is critical here, as well, is the existence of organize pressure and the existence of non-state actors who have a degree of sophistication when it comes to navigating the political process.

Strong internal support can be related to the second element since if elected leaders sense a lack of group solidarity or support for the claims being made, they are more likely to avoid stepping in until the group “gets its act together.” This was especially evident during the compensation debate for people infected with Hepatitis C. When the federal government offered limited compensation to those infected between 1986 and 1990, it drove a wedge in the ranks of Hepatitis C activists, some of whom claimed that a limited deal is better than no deal at all, while others complained publicly that all people with Hepatitis C should stand in solidarity, and reject a deal that compensates only some of the victims, and not others.

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<sup>21</sup> Roy L. Brooks, “Reflections on Reparations,” p. 106-107, in John Torpey, John (ed.) *Politics and the Past: On Repairing Historical Injustices*, Lanham, MD: Rowman and Littlefield, 2003.

The last requirement, that claims must be meritorious, is composed of five sub-factors which, taken together, lend moral force to a claim:

- (1) a human injustice must have been committed;
- (2) it must be well documented;
- (3) the victims must be identifiable as a distinct group;
- (4) the current members of the group must continue to suffer harm; and
- (5) such harm must be causally connected to the past injustice.<sup>22</sup>

In the case of tainted blood, it was not difficult for victims to make a causal connection between the harm they continue to suffer and the past injustice. As regards group distinctiveness, this was less challenging for people with hemophilia than non hemophiliacs, mainly because hemophiliacs already shared a collective identity, and had a long established organization – the Canadian Hemophilia Society – dedicated to defending and advancing their interests. Although victims worked tirelessly to document the tangled web of decisions and non decisions that contributed to the contamination of the blood supply, the report of the public inquiry served as the defining document that outlined the tragic details of this story.

Finally, two factors coalesced to rouse activists and to amplify their “injustice frame.” First, one of the main culprits (the Red Cross) was associated with altruism. Prior to the news of the scandal, the Canadian Red Cross was one of the country’s most venerated institutions.<sup>23</sup> The Red Cross had stood as a powerful reminder of the kindness and generosity of strangers to those in need. As one observer noted in an interview, “the

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<sup>22</sup> Roy L. Brooks, “Reflections on Reparations, p. 107, op. cit.

<sup>23</sup> Historian John F. Hutchinson recalls, in a book examining the historical roots of the International Red Cross Movement, “the enduring legacy of his childhood experience ... was an implicit belief that the Red Cross was beyond criticism. It was as unthinkable to make negative comments about the Red Cross as it was to desecrate the graves of fallen soldiers.” (p. 1) See Hutchinson’s *Champions of Charity: War and the Rise of the Red Cross*. Boulder, Colorado and Oxford, UK: Westview Press, 1996.

Red Cross was like Santa Claus. And it was like trying to prove that Santa Claus was a pedophile.”<sup>24</sup>

Ironically, the Red Cross’s positive image initially helped activists to establish a frame of injustice because it seemed almost unconscionable that a non-profit organization that was created to look after others would instead play a key role in harming them. For instance, in one particularly fiery exchange at the Inquiry between Justice Krever and Douglas Lindores of the Canadian Red Cross, the Commissioner asked pointedly why the organization had failed to apologize to Canadians infected through the blood system. (The federal government officially apologized in 1997 at a news conference organized to respond to the Inquiry’s final report.) When asked during a radio phone-in show, Lindores had said that the Red Cross was waiting for “Krever to do his work” before it could make any decision regarding issuing a public apology:

THE COMMISSIONER: ... Now, quite frankly I do not think that is the reason why the Red Cross has not apologized, the fact that I am conducting this Inquiry. And I am going to put to you what I think is the reason and you can tell me how wrong I am, if I am wrong. The reason why the Red Cross has not apologized is because it was contractually bound by a contract called a “policy of insurance” not to make any admission of liability. And the concern is that an apology might be construed as an admission of liability which would lose the Red Cross the coverage and protection of an insurance policy. Am I wrong?

LINDORES: It is a complicated question, sir, and I wish I had a simple answer for you.

THE COMMISSIONER: I think it is a simple question, Mr. Lindores.

LINDORES: In terms of the statement that I made and the answer on the telephone I would stand by that statement. With respect to your question, it is my understanding that that is also the situation.

THE COMMISSIONER: Now, I am not clear about that answer. That is the situation, you mean the fact that you are contractually bound not to make an admission. Is that what you mean when you said, “that is the situation”?

LINDORES: Yes, that is I believe the situation, yes.

THE COMMISSIONER: Well, is that not the reason the Red Cross has not apologized? Is it because I am conducting an inquiry that you cannot apologize?

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<sup>24</sup> Interview with Dawna Ring, a Halifax lawyer who represented Janet Connors at the Krever Inquiry, Aug. 8, 2001.

LINDORES: ...As the Chief Executive Officer of an organization I have a variety of very complicated responsibilities. And one of them is to defend my organization and my staff and be loyal to them until such time as negligence or some other act requiring apology is in fact proven.

THE COMMISSIONER: I did not understand that. Your position that there is no need for a humanitarian organization to apologize for what happened as a result of the use of its product unless there is a legal finding of negligence? Is that what you are saying?

LINDORES: No, sir, this is an extremely ... emotionally charged environment in which we are all trying to continue to supply this country with a steady and dependable supply of blood products. There are many different factors which enter into the consideration of such a request, not the least of which that you abandoned staff, who in my view, conducted themselves with full credit, during an extraordinarily difficult period and sell them out in order to achieve some short term public relations gain. That is just one of the issues. I have said, unfortunately it is a complicated issue, and it does not lend itself very easily to yes and no answers.

THE COMMISSIONER: Well, I will not pursue this, but I confess I have great difficulty in understanding how an apology from the organization is the selling out and the abandonment of staff. But I do not think I will get any more enlightenment from continuing the discussion. But I confess that is the one thing that I fail to understand in this discussion.<sup>25</sup>

The second factor is related to large-scale accidents, which can serve as powerful mobilizers and contribute to the potential merit of a claim. In the case of “suddenly imposed grievances”, the term coined by Walsh in connection with the nuclear reactor accident at Three Mile Island, “not only are the grievances clear, in addition, relatively straightforward causal attributions can be made, and most importantly the events impose a collective identity upon those affected; everyone is a victim of the same accident.”<sup>26</sup> Although the tainted-blood scandal affected only a small proportion of the population, activists stressed in the media that they were simply the unlucky ones who happened to need a transfusion or relied on blood products. It could have just as easily happened to someone else.

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<sup>25</sup> Testimony, *Commission of Inquiry on the Blood System in Canada*, Nov. 23, 1995, Vol. 217, pp. 45535-45542.

<sup>26</sup> Bert Klandermans, *The Social Psychology of Protest*, London: Blackwell Publishers, 1997, p. 40.

Tainted-blood activists realized that if they were to portray their membership as authentic victims of a gross injustice, it was critical to set their sights on a clearly defined list of enemies. Activists thus centered their attention on three main sets of adversaries: the role of governments (both federal and provincial); the role of the Canadian Red Cross; and, to a lesser extent than in the U.S., the international blood-banking industry. Blood activists reserved much of their finger-pointing for the federal government and the Canadian Red Cross. Private interests have been less the focus of attention, although activists have, as of late, begun implicating pharmaceutical firms in the scandal. The Inquiry singled out Connaught Pharmaceuticals, Bayer, and Miles Canada in its report.

A blaming strategy is also critical for what it obscures, in this case the suggestion that all of those persons who contracted HIV and or Hepatitis C through means other than tainted blood are somehow to blame for their condition. In other words, blaming strategies may define a list of external as well as internal enemies. The internal enemies were, by implicit suggestion, those high-risk persons who donated infected blood, whether knowingly or unknowingly. Not surprisingly, it was a small step from blaming the government to blaming the blood donors, be they homosexuals, drug users, or other at-risk groups, who, it was suggested, were supposed to know better.

In order to mount successful claims, actors also require agency, “the belief that one can alter conditions or policies through collective action.”<sup>27</sup> But the “belief” that one can effect change is insufficient from both a theoretical and an explanatory standpoint. Actors need to mobilize these beliefs into concrete action, and sometimes respond to changes in political opportunity that signal to them that they have the capacity to do so, as well. Although we have established that structural factors influence the beliefs of

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<sup>27</sup> Klandermans, *op. cit.*, p. 18.

collective actors/movement participants vis-à-vis the possibility of change as well as their capacity to act, we must account also for the fact that actors make choices in a given context. It is to the context within which these choices are made that we now turn. Agency is composed of three aspects: collective identity, framing, and strategy.

Collective actors construct an identity around which they mobilize other participants, and demonstrate their “we-ness” to potential challengers. Collective identity, according to Melucci, “is nothing less than a shared definition of the field of opportunities and constraints offered to collective action: ‘shared means constructed and negotiated through a repeated process of ‘activation’ of social relationships connecting through the actors.’”<sup>28</sup> Collective identity formation is an all-encompassing process through which actors produce cognitive frameworks that enable them to survey their immediate environment and to assess the costs and benefits of their actions. Building and constructing a narrative is a critical component of collective identity formation:

In telling the story of our becoming – as an individual, a nation, a people – we establish who we are. Narratives may be employed strategically to strengthen a collective identity but they may also precede and make possible the development of a coherent community, or nation, or collective actor... They connect through narrative reversal the group under conditions of oppression and the group under conditions of liberation. Stories thus explain what is going in a way that makes an evolving identity part of the explanation.<sup>29</sup>

Polletta also stresses that subsuming narrative under the broader category of frame obscures some of the real differences between the two. One of the three main differences centers on how events are linked to outcomes in each one. As she notes, what makes a frame successful “is clear specification not only of the injustice against which protest

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<sup>28</sup> Alberto Melucci, “The Symbolic Challenge of Contemporary Movements,” *Social Research* 52, Winter 1985, p. 793.

<sup>29</sup> Francesca Polletta, “‘It was like a fever...’ Narrative and Identity in Social Protest,” *Social Problems*, Vol. 45, No. 2, May 1998, p. 141.

must be mounted but the agents and likely efficacy of the protest. People must be shown that deliberate action will have its intended effect.”<sup>30</sup> Narrative, she says, works in a different way. It succeeds not only by virtue of what it conveys, but also by what it doesn’t convey:

Individual intention is just one among the principles that may link events in a story. The question in a story is often just what the linkage is: are things happening because of chance or divine intervention, conscious intention, or subliminal drive? This is what grips us, what keeps us listening or reading. A story whose end was immediately apparent would be no story at all – would be the moral without the story.... Narrative necessitates our interpretive participation, requires that we struggle to fill in the gaps and resolve the ambiguities. We struggle because the story’s end is consequential – not only as the outcome but as the moral of the events which precede it.<sup>31</sup>

Polletta suggests that more attention be paid to the role of narrative in movement decision-making processes, since stories are “lenses” through which actors assess the opportunities and obstacles, costs and benefits, successes and failure of collective action. Indeed, when thinking through how reparations claims work their way through political and discursive channels, it is useful to examine the role of narratives, especially those provided by the hundreds of victims who testified before the public inquiry.

The second component of agency, framing, involves “the conscious strategic efforts by groups of people to fashion shared understandings of the world and of themselves that legitimate and motivate collective action.”<sup>32</sup> As Goffman wrote of framing, “There is a sense in which what is play for the golfer is work for the caddy.”<sup>33</sup>

Movements frame the problems/issues they seek to address, and the nature/ substance of their claims. Collective action frames “underscore and embellish the seriousness and

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<sup>30</sup> Francesca Polletta, “‘It was like a fever...’, op. cit, p. 141.

<sup>31</sup> Francesca Polletta, “‘It was like a fever...’, op. cit, p. 141.

<sup>32</sup> Cited in McAdam et al. “Introduction,” p. 6. In *Comparative Perspectives on Social Movements*, op cit.

<sup>33</sup> Erving Goffman, cited in Joseph Gusfield, “The Culture of Public Problems: Drinking-Driving and the Symbolic Order,” p. 202. In Allan M. Brandt and Paul Rozin (eds.) 1997. *Morality and Health*, New York and London: Routledge.

injustice of a particular social condition or redefine as unjust and immoral what was previously seen as unfortunate but perhaps tolerable.”<sup>34</sup> One of the main components of collective action frames is “a sense of injustice.”<sup>35</sup> It “arises from moral indignation related to grievances,” and involves issues of inequality. It may also refer to a feeling that authorities are not dealing adequately with a social problem. As Gamson notes:

The heat of moral judgment is intimately related to beliefs about what acts or conditions have caused people to suffer undeserved hardship or loss. The critical dimension is the abstractness of the target... When we see impersonal, abstract forces as responsible for our suffering, we are taught to accept what cannot be changed and make the best of it... At the other extreme, if one attributes undeserved suffering to malicious or selfish acts by clearly identifiable groups, the emotional component of an injustice frame will almost certainly be there.<sup>36</sup>

The final aspect is strategy. Gamson distinguishes two general types of goals: simple versus multiple, and displacing versus nondisplacing. Of the first type, Marx and McAdam employ the example of student protests against tuition hikes. The dilemma for the movement is choosing between a single issue (reduction of the tuition hike) or addressing a wide range of student grievances. Each strategy has its strengths and weaknesses. A single-issue organization that successfully achieves its goal may face extinction, and may have difficulty in attracting a broad base of support than it would if it were addressing multiple issues. On the positive side, an organization pursuing a single issue can successfully stave off dissension and factionalism within its ranks. A multiple-issue approach is particularly useful in that it allows an organization that has achieved a particular goal to shift its energies to other goals, thus providing some degree of

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<sup>34</sup> Robert Benford, “An Insider’s Critique of the Social Movement Framing Perspective,” *Sociological Inquiry*, Vol. 67, No. 4, November 1997, p. 416.

<sup>35</sup> Gamson, cited in Klandermans, *The Social Psychology of Protest*, op. cit., p. 17.

<sup>36</sup> Gamson, quoted in Donatella Della Porta and Mario Diani, *Social Movements: An Introduction*, Blackwell Publishers, p. 70.



organizational longevity. Alternately, however, multiple-issue organizations may spread too thin the resources and energies of the SMO.<sup>37</sup> In addition, this can lead to bitter infighting within the SMO. Gamson's often-cited study of the factors behind social movement success suggests that single-issue groups are more likely to be successful than SMOs addressing a range of goals.

Of the second type of goal, displacing versus nondisplacing, Gamson is referring to actors' attitudes toward their opponents. Displacing goals, as the name suggests, seek to remove or replace the group's opponents. In the case of blood activism, we might think of two opponents: the government in general and the body that oversees the collection and distribution of blood and blood products. As regards the government, movement activists were less adamant in their call for the government's resignation, although their efforts were aided in this regard by the federal opposition political parties, which seized this issue as an opportunity to lambaste the federal government in general, and Health Minister Allan Rock in particular. The second main opponent, the Red Cross, was the target of displacement strategies by movement activists and in this regard, they succeeded, with the announcement of the overhaul of the Canadian Red Cross and its new institutional name, Canadian Blood Services. Whether the movement was instrumental in achieving this is unclear, given the fact that the Krever Inquiry also recommended that the blood agency be revamped.

The next section attempts to make the case for viewing people infected with tainted blood, hemophiliacs in particular, as victims of cultural injustice. This requires, then, that a case be made for viewing people with hemophilia as a cultural group.

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<sup>37</sup> Gary T. Marx and Douglas McAdam. 1994. *Collective Behaviour and Social Movements*, op. cit., p. 109.

## **Hemophilia and the Politics of Stigma: A Community Comes out of the “Clot Closet”**

There is a strong link between injustice (economic or cultural) and stigma. Marginalized groups that suffer economic or cultural indignities are often subjected to stigma, often forced to manage what Goffman has termed a “spoiled identity.”<sup>1</sup> The literature on collective identity, especially within social movement scholarship, assumes that identity is always a positive attribute, and neglects the possibility that collective actors may be faced with the arduous task of trying to reverse or alter the negative identities inscribed upon them. Such was the case with tainted blood recipients, many of whom were feared by the public at large, especially during the 1980s when ignorance about HIV transmission was rampant. In all of the various instances of stigma identified by Goffman, the same sociological features can be found.

An individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated. We and those who do not depart negatively from the particular expectations at issue I shall call the normals... By definition, of course, we believe the person with a stigma is not quite human.<sup>2</sup>

To be infected with tainted blood implies that the person is tainted in some way, leaving aside for the moment the type of infection (Hepatitis C or HIV), and the nature of infection (injection drug use, unprotected sexual activity, transfusion, or the use of blood products in the case of hemophiliacs). Much has been written about the myths that fuelled AIDS hysteria<sup>3</sup>, many of which were based on fears of the unknown. Stigma affects not only the individual who must suffer its effects, but has

very real consequences for actors who are trying to organize politically.

Outside representations or public identity is also crucial, as it allows us to explain how the views of the external public affect the way groups view themselves, and how these views may affect the articulation of individual or group identities.<sup>38</sup> This is important in the context of victims of tainted blood in that their representatives waded into an AIDS discourse that delineated innocent and guilty victims. Hemophiliacs, it was argued, were the quintessential victims, the unwitting victims of a “normal” lifestyle. This contrasts with gay men or IV drug users, who are blamed for pursuing a reckless, “unhealthy” lifestyle. Indeed, according to one account, this perception of the hemophilia community as innocent victims “exculpates them from the stigma of a disease popularly perceived as being acquired through individual agency.”<sup>39</sup>

This is only half of the story, however. Hemophiliacs also suffer the stigma that is commonly experienced by non-hemophiliacs who are HIV positive. As Richard Goldstein asserts, AIDS carriers are marked both by their Otherness and the common humanity they are denied. Although they can infect anyone, they themselves are infected because they are not just anyone: “This paradox amplifies the fear and denial that always surround disease. AIDS is not just contagious; it’s polluting. To catch this disease is to have your identity stolen; to be lowered, body and soul, into the pit of deviance.”<sup>40</sup> Citing the example of hemophiliac Ryan White, an infected Indiana teenager whose case gained notoriety when he was taunted by his community, Goldstein asserts that even the so-called “innocent victims of AIDS must endure the wrath of bigots and fearmongers,

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<sup>38</sup> Hank Johnston, Enrique Larana, and Joseph R. Gusfield, “Identities, Grievances, and New Social Movements,” in *New Social Movements: From Ideology to Identity*, *op. cit.*, p. 18.

<sup>39</sup> Salmaan Keshavjee, Sheri Weiser, and Arthur Kleinman, “Medicine betrayed: hemophilia patients and HIV in the US,” *Social Science & Medicine* 53 (2001), p. 1083.

<sup>40</sup> Richard Goldstein, “AIDS and the Social Contract,” in Erica Carter and Simon Watney, eds. *Taking Liberties*. London: Serpent’s Tail, 1989, p. 84.

thereby dispelling any notion that there are innocent and guilty victims, or good and bad ways to contract HIV. Of the medical response to his condition, Ryan White told an interviewer: “They marked my folders ... They marked ‘fag.’”<sup>41</sup> In another case, the Ray family of Arcadia, Florida had their house firebombed when residents discovered that their three hemophiliac sons were HIV positive.

People with hemophilia constitute a unique “community of suffering”. Although they represent only a small proportion of the population – hemophilia normally affects about 1 in 5,000 males -- this community shares what Davidson calls a “culture of blood”, one which is “bonded by shared bodily fluids, tissues and genetic codes.”<sup>42</sup> Unlike other cultural identities, which are often based on binary terms such as insider/outsider, or self/other, an identity based on blood “would have to be, in the most literal sense, fluid and porous.”

Not surprisingly, the arrival of AIDS was especially problematic for a community made up exclusively of males with compromised health because it forced them to confront their own sexuality as they were now lumped in with gay males, who figured prominently in early constructions of the epidemic. People with hemophilia, who had struggled to live a normal life in the face of often crippling bleeding episodes, were now facing the type of scorn that had been reserved for other minorities such as immigrants or people of colour. As Davidson says, acquiring AIDS through a medical procedure converted hemophiliacs into “nominal queers”, deviants who had inherited the

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<sup>41</sup> Richard Goldstein, “A Death in the Family.” *The Village Voice*, 24 April 1990, p. 15.

<sup>42</sup> Michael Davidson, “Strange Blood: Hemophobia and the Unexplored Boundaries of Queer Nation,” p. 41. In Timothy B. Powell (ed.). 1999. *Beyond the Binary: Reconstructing Cultural Identity in a Multicultural Context*. New Brunswick, N.J.: Rutgers University Press.

“discursive features of social Otherness.”<sup>43</sup> Although it was almost expected that hemophiliacs would be subjected to homophobic taunts, given their association with what was still known as a gay disease (AIDS was first known as Gay Related Immuno Deficiency), Davidson explains that they were also the victims of “hemophobia”, or the fear of blood. Doctors, teachers, health care workers all feared the risk of infection from the tainted blood of hemophiliacs. Moreover, the merging of homophobic and hemophobic discourses is highly gendered, as well, Davidson notes, as bleeders were originally portrayed as “aesthete”, “feminine, and “weak”. Indeed, the gendering of bleeding disorders reveals the degree to which hemophilia is both a cultural and medical construction:

Their vulnerability to physical trauma keeps them from participating in the normal indices of hetero-masculinity – contact sports, physically demanding work, regular working schedules. Their particular genetic configuration as males who receive a recessive gene through their mothers has traditionally identified them as sissies or mama’s boys. As men who bleed internally on a regular basis, hemophiliacs share biological similarities with menstruating women; as men who depend on the blood of others, they occupy a passive or “receptor” position with respect to health delivery systems. As cripples and invalids they contact the American masculine cult of action and energy; that hemophiliacs are, in fact, obsessive risk takers and exercise addicts has not altered the pervasive image of them as emaciated invalids.<sup>44</sup>

Unlike other victims of tainted blood, hemophiliacs have a relatively strong community infrastructure. Their unique struggles helped to cement a lasting bond and inspired strong feelings of kinship. Still, homophobia was strong enough to keep some HIV positive hemophiliacs in what Cindy Patton has called the ‘clot closet’.<sup>45</sup>

Hemophiliacs were already subject to prejudice and schoolyard taunts from classmates who viewed them as sissies because they had special medical needs. The message was

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<sup>43</sup> Michael Davidson, “Strange Blood,” op. cit., p. 51.

<sup>44</sup> Michael Davidson, “Strange Blood,” op. cit., p. 51.

<sup>45</sup> This term is cited in Michael Davidson, “Strange Blood,” op. cit.

clear: it was difficult enough to live life as a hemophiliac, but it would be unbearably difficult to live life as a hemophiliac with HIV, or a hemophiliac suspected of being HIV-positive. Worse still, efforts to raise awareness of hemophilia and encourage people to be candid about their condition would be thwarted by a strong public connection between hemophilia and AIDS.

While homophobia may have prevented some hemophiliacs from organizing politically alongside gay AIDS activists in the early stages of the epidemic, this is not to suggest that hemophiliacs were apolitical. In Canada, the Canadian Hemophilia Society has expanded considerably from its modest beginnings. Its initial focus was on educating the hemophilia community and on encouraging governments and the medical community to provide the necessary infrastructure for hemophilia research. In what many considered a bold move at the time, the organization began to publicly criticize the Red Cross in the 1960s, urging that it be stripped of its monopoly over the blood business. In the 1970s, the group pressured governments to establish comprehensive-care clinics for hemophiliacs, similar to ones created in the U.S. By the early 1980s, the organization had succeeded, with the creation of at least one such centre in virtually every province.

By many accounts, 1987 marked a critical period in the radicalization of the Canadian hemophilia community. The realization that almost half of Canada's hemophiliacs were infected with HIV, combined with the death of the organization's founder that same year, galvanized many in the community, and forced the CHS to abandon two of its main projects to focus on the issue of compensation. One of the main weapons in its arsenal was what later came to be known as the Archival Study, one of the first accounts of negligence in relation to tainted blood prepared by members of the

group. Despite some initial reluctance from the organization's national office, the Ontario chapter of the CHS was among the first to call for a formal public inquiry.

Kirp provides an interesting comparative account of the mobilization of U.S. hemophiliacs and homosexuals in the face of AIDS. Both gay men and hemophiliacs, whom he terms the “odd couple of AIDS,” have been regarded as less than normal, the first group as a result of “deviant behaviour” and the latter by their association with tainted blood. Although they followed different trajectories, both groups responded to AIDS “by internalizing the shame of their circumstance, living closeted lives, concealing or camouflaging the significance of their condition.”<sup>46</sup> Liberation arrived for both groups during the late 1960s, but in different forms. For hemophiliacs, it came in the form of Factor VIII concentrate, which allowed hemophiliacs to self-administer the clotting factor at home and avoid frequent visits to the hospital to be treated for minor bleeds. For hemophiliacs, then, the key to liberation came in the form of a medical ‘magic bullet’, which would allow them to live their lives as normally as possible. According to Kirp, reiterating a claim made in the context of Canada, American hemophiliacs “implicitly trusted their caregivers, the physicians, and the pharmaceutical establishment, which had brought normality within reach.”<sup>47</sup>

The seeds of liberation for gay men, conversely, were sown in the form of a political event (the Stonewall riots in New York) during which they demonstrated a show of defiance against the police. Unlike hemophiliacs, who viewed normality as a medical construct, gays recognized that the very category “normal” needed to be deconstructed. It

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<sup>46</sup> David Kirp, “The Politics of Blood: Hemophilia Activism in the AIDS Crisis,” p. 297. In Eric Feldman and Ronald Bayer (eds.), *Blood Feuds*, op. cit..

<sup>47</sup> David Kirp, “The Politics of Blood: Hemophilia Activism in the AIDS Crisis,” p. 298. In *Blood Feuds*, op. cit. Similar suggestions have been made about Canadian hemophiliacs’ relationship of trust with the medical and scientific communities, which is supported by the fact that doctors and scientists occupied prominent positions in the Canadian Hemophilia Society.

soon became apparent that if they were going to reverse the predominant construction of homosexuals as deviant, nothing less than collective action would be required. And, more important, they would have to focus their energies on attacking the very institutions that reinforced this prejudice. This realization would eventually work its way onto the agenda of AIDS activists, who sought to underscore the “criminal” negligence of governments who did little or nothing to stem the spread of AIDS because of its association with homosexuality. This legacy of distrust of government to do its job would help to spawn the creation of self-sufficient, arm’s length, community-based organizations, something that hemophiliacs, who saw in the medical community allies instead of enemies, severely lacked.<sup>48</sup>

In their analysis of testimony from people with hemophilia at the U.S. inquiry into tainted blood, Keshavjee et al describe a community that is bitter and feels betrayed by the organizations created to look out for their interests (the National Hemophilia Foundation, by government, by blood banks, and by the pharmaceutical industry. Canadian hemophiliacs voiced similar rage, but less of it was directed at their national organization, the Canadian Hemophilia Society, than in the American case. As the authors make clear, what was unique about the testimony offered by people with hemophilia was “their location of blame in the negligence of those whom they believe forsook their care for economic gain.”<sup>49</sup>

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<sup>48</sup> Relations between people with hemophilia and medical staff were not always pleasant, however. Janet Conners explained in an interview that hemophilia clinic staff warned her husband, Randy, that if he did not behave responsibly (e.g., avoid alcohol), he could be denied important treatment. “They [the nurses and staff at the hemophilia clinics] thought that these patients were somehow their boys. There was always a constant threat hanging over their heads that if they weren’t good little boys, they were going to lose their home care. The hemophilia nurse said if Randy was drinking too much, he was going to lose his home care.” (Interview with Janet Conners, Aug. 11, 1999)

<sup>49</sup> Salmaan Keshavjee, Sheri Weiser, and Arthur Kleinman, “Medicine betrayed: hemophilia patients and HIV in the US,” *Social Science & Medicine* 53 (2001), p. 1084.



The authors also emphasize the connections made by hemophiliacs to the Jewish Holocaust in Nazi Germany, itself one of the most potent symbols of “collective calamity.” To be sure, this is not the first time this image has been invoked. In the early stage of the epidemic, the AIDS movement was able to construct a compelling narrative around government neglect (some of the more militant voices invoked the genocide metaphor<sup>4</sup> to illustrate the government’s response to AIDS), and made a convincing case that governments failed to respond to AIDS because they deemed the gay community, in particular, to be a disposable population.<sup>50</sup>

Davidson takes the AIDS community (and the larger “queer community”) to task for failing to include HIV-positive hemophiliacs within the borders of a “queer nation,” noting that the concept of queer should be wide enough to accommodate “a wider matrix of constituencies than those usually defined by ‘gay’ and ‘lesbian’ . If so, these constituencies might include figures usually (but not exclusively) defined as heterosexual.<sup>51</sup> While hemophiliacs played a pivotal role in “securing an image around which legislation, research, and public policy could be made without having to engage issues of homosexuality and homophobia,”<sup>52</sup> they were marginalized from the dominant, gay-dominated AIDS discourse.

## **Conclusion**

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<sup>50</sup> For an interesting discussion of the use of the genocide metaphor in two competing movements, see Arlene Stein, “Whose Memories? Whose Victimhood? Contests for the Holocaust Frame in Social Movement Discourse,” *Sociological Perspectives*, Vol. 41, No. 3, 1998, pp. 519-540.

<sup>51</sup> Michael Davidson, “Strange Blood...” op. cit., p. 55.

<sup>52</sup> Michael Davidson, “Strange Blood...” op. cit., p. 51.

This paper has attempted to think through the implications of adopting a cultural injustice frame to understand tainted blood compensation, paying particular attention to the case of the hemophilia community, the so called “canaries in the mine shift.” Thousands of people with hemophilia died as a result of putting their trust in their country’s respective blood systems. Were it not for this unfortunate ‘lottery of death’, many thousands more may have died. The focus of government attention has been on compensating those who have suffered most. People who contracted HIV through the blood system, therefore, were awarded more generous packages than those who were infected with Hepatitis C., which, up until 1990, did not even have an official name. It was known by what it was not (non A, non B Hepatitis). Moreover, people with a positive Hepatitis C who qualified for government compensation are categorized according to severity of illness, and compensated accordingly.

Although the reparations literature is deficient in some respects with regard to positioning victims of ‘iatrogenic illness’, I argue that one can rightly claim that people with hemophilia were subjected to a form of cultural injustice in that they were infected as a result of their membership in a particular community. Documents presented at the Inquiry indicate that blood system officials deliberately chose to give people with hemophilia blood products that were contaminated on the assumption that they were already infected anyway given their frequent use of blood products. People with hemophilia were singled out precisely because of their medical condition, and their reliance on blood and blood products.

This paper has not tackled the broader, more complex question of whether others who were not infected through the blood system are owed compensation. Illingworth, for

instance, has argued that gay men and intravenous drug users who contracted HIV should receive financial compensation because they were not engaging in autonomous behaviour, that is, in accordance with the desires they have come to support. Men who engage in impersonal sex are responding to a repressive morality vis-à-vis sexual expression. Had society not discriminated against them in the first place, she argues, the need for liberation from an effeminate, passive stereotype would not have existed: “American homosexuals were cultivating the macho stereotype ... that straight men under the influence of feminism, were abandoning. Giving up promiscuous sex meant giving up a hard-won *positive* identity, going back to the Nellie stereotype.”<sup>53</sup> As for IV drug users, because the behaviour in which they engage is illegal, they are *forced* to perform these activities in ways that ultimately endanger their lives.”<sup>54</sup> It is beyond the scope of this paper to judge the validity of Illingworth’s argument. Rather, I introduce it here to underscore the fact that the term “innocent victim” is not necessarily the privileged refuge of the hemophiliac. In today’s “risk society”, there are countless victims, some of whom lack the agency to mobilize the requisite frames of injustice. Prior to the 1980s and the arrival of AIDS, people with hemophilia lacked any sense of agency, and had not yet transformed themselves from a community of suffering to a community of action. Perhaps, other victims of the risk society may choose to convert their suffering into action.

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<sup>53</sup> David Black, quoted in Illingworth, Patricia. *AIDS and the Good Society*. New York and London: Routledge, 1990, p. 77.

<sup>54</sup> *Ibid.*, p. 82.

## Appendix: Chronology of Compensation Debacle

- Sept. 1988 Recipients of HIV-infected tainted blood make their first formal requests for compensation.
- Dec. 14, 1989 The federal government announces its carefully-worded Extraordinary Assistance Plan, which provides \$120,000 over four years to each hemophiliac or transfusion recipient infected with HIV through the blood system. The decision sparks little internal debate within government and media circles, perhaps not surprising given the holiday season.
- Oct. 1990 A report commissioned by the Ministers of Health says Canada should institute a no-fault insurance system for all victims of 'medical misadventure'.
- March 1993 Ontario court begins to hear case filed by Rochelle Pittman, whose husband contracted HIV during the course of heart surgery. During the trial, it was revealed that the family doctor knew but never told Mr. Pittman that he had received blood from an infected donor. Rochelle Pittman only found out she was positive after her husband's death.
- April 1993 With the federal plan one year away from expiring, tainted-blood recipients begin to urge the provinces to compensate.
- April 1993 In a bold move, the Nova Scotia government breaks ranks with the provinces and decides to compensate recipients of HIV-tainted blood, offering them \$30,000 annually for life. Nova Scotia AIDS activists Randy and Janet Connors are credited with persuading Health Minister George Moody to go it alone.
- Sept. 15, 1993 The 11 remaining provinces and territories follow suit, announcing a \$30,000-a-year compensation package.
- Oct. 1993 Government announces a formal public inquiry to examine the circumstances surrounding the tainted-blood tragedy.
- Nov. 22, 1993 Ottawa lawyer Pierre Lavigne, representing a group of little-known Hepatitis C patients, is granted standing at the opening of the Commission of Inquiry on the Blood System in Canada.
- March 14, 1994 Ontario court rules in favour of Pittman, and awards her more than \$500,000 in damages. Madam Justice Lang warned that the

decision was “fact-specific” and should not be taken to apply broadly. Nonetheless, tainted-blood activists laud the decision.

- March 15, 1994      Deadline for tainted-blood recipients to accept provincial compensation package. In return for compensation, they must waive the right to sue the Red Cross and federal and provincial governments. Most recipients accept the plan, feeling they have little choice. Many, however, decry the timing of the deadline, only one day after the Pittman judgment, which lawyers had to scramble to digest, and well before the release of the Krever inquiry report.
- Oct. 1994              The Canadian Hemophilia Society leaks the results of a 1992 study suggesting that as many as 12,000 people may have needlessly contracted Hepatitis C as a result of a Red Cross decision to forego testing. Justice Krever lashed out at the Society for leaking the study, which was obtained through federal access-to-information legislation, to the media before presenting it to him at the Inquiry.
- May 1994              Newly formed Hepatitis C Survivors’ Society is granted standing at the Inquiry, but the organization decries the Commission’s refusal to grant it intervenor funding.
- May 26, 1994        Federal Health Minister Diane Marleau angers many in the tainted-blood community by scoffing at calls for Hepatitis C compensation.
- Sept. 10, 1996        Federal and provincial health ministers meet to discuss issue of Hepatitis C compensation.
- Sept. 19, 1996        The first class-action lawsuit on behalf of people with Hepatitis C is launched in British Columbia.
- Oct. 10, 1996        Ontario Health Minister Jim Wilson tells people with Hepatitis C that their only recourse is to sue, which touches off a flurry of protest activity.
- Oct. 11, 1996        Hepatitis C activists stage a hastily assembled protest on Parliament Hill; they are virtually ignored by MPs.
- July 24, 1997        Health Minister Allan Rock announces for the first time that compensation may be extended to people with Hepatitis C.
- July 25, 1997        Ontario follows the lead of British Columbia in launching class-action suit on behalf of people with Hepatitis C.

- Nov. 17, 1997 Federal Health Minister Allan Rock promises people with Hepatitis C that their claims will be dealt with humanely.
- Nov. 27, 1997 Justice Horace Krever releases long-awaited final report on the scandal. In the three-volume report, Krever urges governments to compensate all tainted-blood recipients. “Compensating some needy suffers and not others,” he writes, “cannot be justified.”
- Dec. 2, 1997 Quebec becomes the first province to formally support extending compensation to all recipients of Hepatitis C-tainted blood.
- Feb. 4, 1998 A poll by Angus Reid suggests that 87 per cent of Canadians support the idea of extending compensation to all people who contracted Hepatitis C through the blood system.
- Feb. 17, 1998 Federal and provincial health ministers meet again to consider the Hepatitis C compensation issue.
- March 10, 1998 Ontario lawyers launch another class-action suit, this time on behalf of people with Hepatitis C infected prior to 1986 and after 1990.
- March 27, 1998 Government announces \$1.1 billion compensation plan, restricted to people infected with Hepatitis C between 1986 and 1990. Details of the plans have yet to be ironed out.
- April 3, 1998 Angered by the limited package, Hepatitis C activists stage protest on Parliament Hill; Reform Party vows to push the issue.
- April 7, 1998 Former federal Health Minister Monique Begin breaks her silence, and suggests in an interview that the Liberal government should compensate all people with Hepatitis C. Begin served as health minister from 1977 to 1984 – the period during which the blood supply was first contaminated with HIV and Hepatitis C.
- April 20, 1998 Hepatitis C activists stage another protest; support grows among the other federal political parties, led by the Reform Party.
- April 22, 1998 Prime Minister Chrétien rejects a call for a free vote in the House of Commons, ordering that a vote on compensation should be viewed as a vote of confidence in the government.
- April 28, 1998 In a dramatic vote, the House of Commons rejects the Reform Party-led motion on extending compensation, 155-140. Liberal

MP Carolyn Bennett, a former board member of the Hepatitis C Society of Canada, votes against the motion.

- May 1, 1998      The federal government is angered by the about-face of the Quebec, Ontario, and B.C. governments, each of which had initially supported the limited deal, but broke ranks to throw their support behind an extended package.
- May 4, 1998      Much to the ire of the federal government, Ontario Premier Mike Harris promises to compensate all people with Hepatitis C who were shut out of the package.
- May 5, 1998      Compensation deal is reopened.
- Dec. 1998      Class-action lawyers leak the details of the \$1.1 billion aid package, which would compensate those infected between 1986-1990 on a sliding scale, with the most money going to the sickest. The package also covers people who were “secondarily infected” with HIV.
- Feb. 24, 1999      A group of tainted-blood recipients announces in Washington, D.C., plans to file a \$660-million class-action lawsuit against the U.S. government, the states of Arkansas and Louisiana, and the Food and Drug Administration, in connection with the “unlawful and willful collection and distribution of contaminated blood and plasma from prisons in the U.S.” Among those implicated by their accusation are then-governor of Arkansas, Bill Clinton, and current finance minister Paul Martin. The suit alleges that while the FDA suspended the use of prison plasma to manufacture blood products in 1982, it allowed this plasma to be exported to Canada.
- May 1999      Thieves break into the offices of the Quebec chapter of the Canadian Hemophilia Society, stealing a computer, three telephones, and documents related to the blood scandal. On the same day, an Arkansas prosthetics clinic owned by Michael Galster is firebombed. Galster is the author of *Blood Trail*, a fictional account of how the prison-plasma program worked. Mike McCarthy, a hemophilia activist who appeared as the lead plaintiff months earlier in Washington, tells the media that he is convinced that the two crimes are linked.
- June 1999      Federal, provincial, and territorial governments and counsel for people with Hepatitis C file a proposed settlement agreement with the courts for final approval. As it seeks to settle class-action lawsuits in Ontario, British Columbia, and Quebec, the deal must be approved by the courts in these provinces.

- July 1999 News is leaked that class-action lawyers across Canada who negotiated the compensation deal for those infected between 1986-1990 will earn as much as \$52.5 million for their efforts. The Hepatitis C Society of Canada holds a news conference at which they criticize the move.
- July 1999 The Quebec government passes an order-in-council in the National Assembly, offering a one-time cash payment of \$10,000 to people who contracted Hepatitis C before 1986 and after 1990, the period not covered by the \$1.1 billion package. Quebec recipients lash out at the payment, arguing that Premier Lucien Bouchard reneged on his commitment to first consult those most affected.
- Aug. 1999 Court hearings begin on settlement of class-action suits in Quebec, Ontario, and British Columbia.
- Aug. 2000 Hepatitis C recipients who were infected between 1986 and 1990 approve a plan from the Canadian Red Cross Society that awards them \$79 million in assistance. The deal was critical in ensuring that the Red Cross avoid bankruptcy as well as many lawsuits that had been launched against it by tainted-blood recipients. The deal, which was brokered by former Ontario Premier Bob Rae, was justified by its supporters on the suggestion that forcing the Society into bankruptcy would hurt others throughout the world who benefit from the humanitarian efforts of the Society.
- Nov. 2000 The British Columbia government agreed to provide \$6.5 million to settle a class-action suit launched on behalf of Hepatitis C recipients infected before 1986 and after 1990. The deal works out to about \$5,000 for each person involved in the class action.
- Jan. 2001 The Manitoba government announced a provincial compensation plan for Hepatitis C recipients shut out of the federal-provincial package of which Manitoba was a part. Recipients will receive a one-time payment of \$10,000. In addition, the province agreed to cover the cost of Rebetron, a drug treatment for Hepatitis C, at a cost of \$19,000 per patient per year.
- June 26, 2001 An Ontario judge approved a Canadian Red Cross assistance plan to Hepatitis C recipients who were shut out of the federal-provincial package. Justice Warren Winkler, who had rejected a Red Cross offer in February, said the revised settlement was “fair, reasonable, and in the best interests of the class as a whole.”



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<sup>1</sup> See Erving Goffman. 1963. *Stigma: Notes on the Management of Spoiled Identity*,

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<sup>2</sup> Erving Goffman, "The Stigmatized Self," from *Stigma: Notes on the Management of Spoiled Identity*. In Charles Lemert and Ann Branaman (Eds.). 1997 *The Goffman Reader*. Malden, Massachusetts, and Oxford, UK: Blackwell Publishers, p. 73.

<sup>3</sup> These fears were not unwarranted. In the late 1980s, for instance, the citizens of Arcadia, Florida set fire to the house of the Ray family, whose three hemophiliac children had HIV.

<sup>4</sup> For an interesting discussion of the use of the genocide metaphor in two competing movements, see Arlene Stein, "Whose Memories? Whose Victimhood? Contests for the Holocaust Frame in Social Movement Discourse," *Sociological Perspectives*, Vol. 41, No. 3, 1998, pp. 519-540.