

1. BACKGROUND

Please describe your connection to this case.

My name is Janet Conners. I live at 15 Sarah Crescent, Hatchet Lake, Nova Scotia. My date of birth is January 4, 1956.

I am the widow of a hemophiliac. My late husband, Randy Conners was a Factor VIII hemophiliac and became infected with HIV from blood products and I became infected with HIV through sexual relations with my husband. I am one of hundreds of secondarily infected spouses and children with HIV, from blood in Canada.

Randy used blood products, for the most part to prevent bleeding and to prevent a worsening of arthritis. Randy never had a life threatening bleed.

Randy was diagnosed with HIV in 1986. I was diagnosed with HIV in July 1989. We disclosed our HIV status to our son in 1991, when he was just 11 years old. I was diagnosed with AIDS in July 1994. Randy died of AIDS related complications September 13, 1994.

Randy, with a group of other HIV positive hemophiliacs founded a national organization named Canadian Hemophiliacs with HIV. They wanted the ability to be represented and to speak for themselves publicly and at the Krever Inquiry into Canada's Blood system.

I founded a national organization for those who were secondarily infected with HIV, named (Janet Conners) Infected and Spouses Association. We are an ad hoc group comprised of mainly women and children. I believed it was necessary to start this group because it seemed to me that we were the forgotten, ignored and neglected group of persons infected with HIV by Canada's Blood System. I believed we needed our own council and the ability to speak for ourselves publicly and at the Krever Inquiry into Canada's blood system. Our roles in and our needs from the blood community were and are vastly different from those directly infected with HIV.

The secondarily infected group is comprised mostly of women and children. We were infected with HIV, and often the primary caregiver for our HIV infected husbands/partners and our HIV infected children. Women were viewed as having one of two roles, caregivers or vectors of HIV. We cared for our sick and dying husbands/partners and we passed the disease on to our children. It has been recognized, in Nova Scotia, for example, that we, the partners and children, were equally harmed by the actions or inactions of the Canadian Red Cross, as operator of Canada's Blood System.

One of the first facts known about HIV is that it was transmitted sexually. This was learned through scientific study of HIV transmission in the gay community. There has never been a sexually transmitted disease that was known to be transmitted homosexually that was not transmitted heterosexually.

The Canadian Red Cross Society knew HIV was also transmitted by blood; that HIV caused AIDS and that AIDS caused people's death – it is a 100% fatal disease. The blood product Randy used was made from 60,000 to 200,000 blood donations per vial. Heat treating the blood product would have killed the HI virus. The Canadian Red Cross Society knowingly depleted its stocks of non heat treated product. They had a stockpile of safer heat treated products on their shelves. It did this without telling hemophiliacs or their partners.

Without our knowing the Canadian Red Cross Society was distributing a product that would kill us, Randy and I continued a usual sexual relationship. I became infected with HIV. I will die from the effects of this disease

The Canadian Red Cross Society failed to advise Randy and I and other recipients of blood and/or blood products of these facts. The Canadian Red Cross Society failed to warn the sexual partners of these facts. Randy and I and other recipients and their sexual partners were denied the ability to protect ourselves from infecting or becoming infected with HIV, through sexual activity. Couples were denied the ability to make informed choices about having children who would be born without HIV infection. Partners and children of recipients became infected with HIV. Many of those partners and children have already died. We, the surviving infected partners and children, have a disease that is fatal. None of us received blood or blood products; “adulterated drug”, however we will all die as a result of that adulterated drug and the Canadian Red Cross Society's failure to warn.

2. EMOTIONAL LOSS

Please describe how the offence affected you emotionally.

Randy was a son of Dorothy and Percy, a husband to me, a father to Gus, a brother to Judy, Larry and Kim, a son in law, a brother in law, an uncle, a cousin, a nephew, a grandson, a friend, a coworker. Randy had a wonderful sense of humor and loved to make others laugh. He was a marvelous storyteller. Family was the most important thing in Randy's life. He loved computers, computer games, Star Trek, music, traveling, fishing, good food, friends, he especially loved Christmas and its usual traditions and he loved continuing his family traditions and sharing them with Gus and me. Randy loved Gus so much that he adopted him after he and I married. He was a fabulous father to Gus and took his role a father very seriously. I have never met anyone who loved life, loved being alive and was so alive as Randy. We all miss him very, very much. My son and I speak of him nearly every day. I don't think our son will ever fully recover from the death of his father. Gus was just 14 years old when Randy died.

I am the daughter of Don and Irene Pritchard, the widow of Randy, wife of Terry, mother to Gus, a stepmother, a sister to Ross, Lois, Norma, Don, and Ruth, an aunt, a sister in law, a daughter in law, a niece, a friend, an activist. I enjoy travel, I love my family and the time I spend with them. I love Christmas, and parties and my friends. I love to garden.

Randy and I met in December, 1985. We married in August, 1987 and lived in Halifax until we bought a house in Dartmouth. We were very happy. We had a fairly ordinary life, with the same plans, hopes and dreams as others of our age.

I don't believe I have the words to describe how the offence has affected me emotionally. I would like to share some stories of Randy's and my life and hope these stories can help the court to understand how the offence affected me emotionally. If Randy and I had not been infected with HIV, none of these things would have happened.

Randy had previously tested positive for Hepatitis B and that hadn't seemed to have any impact on his health. We believed HIV was just one more harmless thing in the blood that Randy had been infected with. He was being treated at both the Hemophilia and Infectious Diseases Clinics in Halifax.

There were two events that occurred closely to each other which forced us to come to terms with the seriousness of his HIV infection. The first was when I tested positive for HIV and the second was while Randy was completing the application form for Federal Compensation.

Randy and I had been told, separately and together, that there was very little chance that I would become infected with HIV. Randy was told that hemophiliacs did not seem to be infecting their wives, so he should use condoms only if he wanted to. I was told that, after nearly 3 years of being tested on a quarterly basis, I was probably immune to HIV infection. We were told that it was believed that "something" happened to the virus when

it entered the body of a gay man, rectally and that was why hemophiliacs were not infecting their wives. None of this was based on science. In fact, science had proven the exact opposite of this to be true, as I mentioned in my opening remarks.

While receiving my test results, I was told that not much was known about HIV in women, but they did know that the average time from diagnosis to death was about 6 months. We were stunned beyond words at my positive test result. We simply sat on our bed, held on to each other and cried. We tried to convince ourselves the test results were incorrect. We said that we would demand a re-test. We realized that day, that Randy would die from HIV. We believed that I would most likely not be alive by Christmas. We were devastated at the thought of Gus being left an orphan. We knew we had to make plans for Gus' future. We discussed that Randy had not yet adopted Gus and that he wanted to start that proceeding as soon as possible. Gus was eight years old. We were absolutely terrified of the adoption process, in case Social Services found out that we were both HIV positive and took Gus away from us. We had heard stories of parents who were HIV and had had children removed from their homes.

In 1989 there was stigma and a seemingly acceptable discrimination toward persons infected with HIV. In our own province, Eric Smith, a school teacher who was HIV positive had been very publicly, fired from his job. In the US, Ryan White, a young hemophiliac was thrown out of his school when it was learned that he was HIV. We were frightened of what might happen to us but we were very, very frightened of what might happen to Gus.

We agreed that we would each tell one of our sisters, Randy, his sister Kim and I, my sister Ruth. We agreed that we would tell no one else, not even Gus. I asked Ruth if she would agree to become Gus' guardian when Randy and I died. We felt that for every day we didn't have to tell Gus, it would be another day of carefree childhood for him.

From that summer day in 1989, until the winter of 1990, we lived a lie. We believed it was the only way to manage our lives. We received very little support, no emotional support except from each other. It was a constant struggle and caused an enormous strain in our marriage. There were some occasions, when the strain was so great that we talked of divorce. We could not be honest with each other about so much of what was happening in each of our lives and our life together. If I got a cold, Randy was terrified that I was going to die. I would feel the same fear, but I couldn't talk to Randy about my fears. I knew that he felt great guilt over my infection. Randy suffered in silence and tried to cope with his feeling of guilt. There came a time when Randy was able to voice his feeling of guilt to me. If you can imagine for a moment, the sound of a whispered yell and a voice strangled by horror and disbelief, then you will know how Randy's voice sounded that day. He said to me, "How do you think I feel? I killed my wife!", and then he wept. He cried for a very long time that day, he cried uncontrollably. I told him that wasn't true. I told him the blood system was responsible. I tried to comfort him as best I could. We were overwhelmed and alone.

About 6 weeks after I was diagnosed, while he was completing the application form for Federal compensation Randy had a conversation with one of his doctors. She informed him, by phone at about 9 p.m., on a Thursday evening his blood work had indicated for quite some time that his HIV infection had progressed to a clinical diagnosis of AIDS. She told him she and the clinic staff decided not to tell him; they were waiting to tell him at a time that would “shock him out of his denial”. Once again, we were stunned. Then we became angry; probably angrier than either of us had ever been. This was the moment that we decided that we could not remain silent and alone any longer. We decided that Randy would only be treated at the Infectious Diseases clinic and that we would attend all our medical appointments together. Randy began AZT a drug to treat HIV and Septra a drug to help prevent PCP, which I will discuss further under the Health Impact section.

I said at the start of this section that I don't believe I have the words to describe the emotional impact of this offence on my life. Perhaps there are no words to describe it. I feel angry that this happened and that it happened to us, I feel the loss, not just of Randy's life, but the loss of the life we might have had. Our son Gus said to me, recently “That's the wedge in my life, Mum. I struggle to come to terms with who I am and who I might have been if Dad could have lived.” Gus has said, that while he remembers events in his life prior to that time, he cannot remember a time when Randy and I were not HIV positive. Soon after we told him that we were both HIV positive and would die from this disease, Gus told me he didn't know how to feel joy any longer. As a mother, I hope my son to be happy and his life filled with joy. I felt I had failed as a mother.

I said that Randy loved music. He encouraged Gus to love music, as well. He took Gus shopping one day and bought him a beautiful saxophone. Gus took lessons and joined both the school band and a city band. Four days before Randy died, he asked Gus to play a song on his sax for him. Gus sat on the side of his father's bed and played a few songs and then just fooled around with the sax, making his father laugh. The day Randy died, Gus put the saxophone in it's case and has never played it again. A few months after Randy died, Gus gave his saxophone to a younger cousin. He told me he wanted someone to play his Dad's sax, but he couldn't. Gus was also a member in three vocal choirs. After Randy died, he quit all three choirs. He didn't sing again until he was in grade twelve, nearly four years after Randy died. As a mother I can't begin to describe the feelings and emotions I experienced at the loss of music and song caused in my son's life.

My family, my friends and I try to cope with our emotions every day. We live with fear, especially as more and more HIV drugs fail me that I will die soon. At times we feel grief at the thought of the future. We try to live with hope and happiness each day that I am alive but we know I will eventually die from this disease. Every day is a struggle for me to try to cope with side effects from the drugs I take. These drugs have been referred to in the media as a cocktail or combination therapy – pretty words for what is in reality, chemotherapy. They are a chemical based therapy for the treatment of HIV infection. The difference between me and a person with cancer receiving chemotherapy is they receive a course of treatment for a set amount of time. They get a break from treatment.

I will be on this chemotherapy until none of the drugs have any effect any more, which means I will have become resistant to all HIV drugs or I die. I have lost muscle mass, body fat, suffered a myocardial infarction. I have frequent nausea, diarrhea, fatigue, loss of the ability to concentrate, loss of memory and the awareness of this loss. I am afraid of not being able to remember. I am afraid of dementia. I rarely have the strength or energy to work in my garden, any more. On a good day, I feel only nausea, fatigue and some weakness.

I am disappointed in a system that was meant to save life, and a system of government that was meant to protect its citizen. I am angry. I am angry about all that has happened to us; to me. I am frustrated and angry that this process of inquiry, criminal charges and sentencing. I am nearly exhausted by these events and the reliving of these emotions. I crave a fair and just ending to these proceedings. I wish to be able to finally rest and just live in quiet peace.

3. HEALTH IMPACT

Please list the ways in which your physical health or the health of your loved ones has been affected, including treatment you received and any permanent disabilities.

HIV is a terrible disease. In very simple words, this virus attacks and destroys the immune system, leaving a body susceptible to any number of illnesses. Any of those illnesses may be fatal. Often, before a person dies of AIDS related complications, they will suffer from wasting syndrome, possibly pneumonia, cytomegalovirus, which can cause blindness, various cancers, lung infections to name just a few of the more common opportunistic infections. Many of these opportunistic infections are treatable today, however the treatments are not without side effects. Sometimes the side effects are so overwhelming, that a person cannot continue with the treatment.

I watched Randy suffer from wasting syndrome. The feeling of utter helplessness caused by watching my husband, slowly starving is indescribable.

I struggle constantly with wasting syndrome. I understand how my family feels at those times, almost overwhelmingly frightened that I will die because I am unable to eat. I know the unreasonable feeling of anger at the person who is unable to eat. I felt, wrongly, at times, that if Randy would just try harder, he would be able to eat. I know now, that no matter how hard I try when I have wasting syndrome, I just can't eat and if I do, I will most likely just throw up. Sometimes, it is easier to not try to eat, because the vomiting is so difficult.

Randy began treatment for HIV in 1989 or 1990. He started AZT and Septra, a prophylactic treatment for PCP. He was severely allergic to Septra. He developed a skin rash covering his whole body, his eyes were swollen nearly shut, and he was hospitalized to treat the reaction. He then began a dapsons, another prophylactic treatment for PCP. He was also allergic to this drug. He was then treated with pentamidine, another prophylactic treatment for PCP. At first, this was an inhalant treatment. Eventually he developed PCP and had to be treated with inter venous pentamidine. Randy experienced severe side effects from this drug. After he was successfully treatment, he continued on inter venous pentamidine, receiving treatment every four weeks. This was a somewhat complicated process. Prior to receiving pentamidine, he would be given inter venous gravol. Once that was complete his pentamidine treatment was started. This drug caused severe vomiting, so it had to be administered very slowly. This process usually took 5 to six hours, and he would have to rest for about an hour, before he felt well enough to leave the outpatient clinic. He eventually developed diabetes, possibly as a side effect from this treatment. He was insulin dependent until the end of his life. Each time he was developed break through pneumonia, the time between prophylactic treatments would shorten, from 4 weeks to 3 weeks, to 2 weeks until a time he no longer received prophylactic treatment for PCP.

From 1990 until his death in 1994, Randy developed PCP at least 5 times. There were two occasions when a definitive diagnosis of PCP was not able to be made,

however he was treated for PCP. Each time he developed PCP, he was hospitalized and each stay lasted longer. While Randy was hospitalized, he would often be visited by interns and medical students. A few of them told us that hemophilia was a disease that they only read about in a text book and to meet a hemophiliac was quite a rarity. Some would ask if they could examine him, others would not be even polite enough to ask. They would simply come into his room, introduce themselves and begin a physical examination. They would poke and thump him, examine his legs, often moving, bending and twisting his knees and ankles. It was clear that while they may have read about hemophilia in a textbook, they had no real understanding. More often than not, these examinations would cause Randy to bleed in his muscles and his joints. He would then have to receive treatment of Factor 8, a blood clotting agent. His joint would swell, and become very painful. He would not be able to walk for a number of days. When we complained about these unnecessary examinations, we were told that the hospital was a teaching hospital, and these students had to learn on someone. I began to tell medical students and interns that they could not examine Randy any longer.

As Randy was hospitalized more often and for longer periods of time, we had to shift our family life from our home to the hospital. I would drive Gus to school, and then go to the hospital to care for and spend time with Randy. At about 3 p.m., I would get our son from school and bring him to the hospital. He would spend time with Randy, doing his homework, sometimes with Randy's help, if Randy was well enough, Randy and Gus would cuddle in Randy's hospital bed watching a little TV together. Usually my parents would stay in our home during this time. Either I would drive Gus home or my parents would come to the hospital to get Gus. During these times, in order to have a family meal together, I would buy food from the hospital cafeteria or from a take out restaurant. Gus rarely got to bed at his bedtime. I would often spend the night in the hospital, sleeping in a chair in Randy's room.

As hospital budgets were being cut, we could see and experience a lessening of care. One night, at about 2 a.m., I received a phone call from a nurse, asking me to come to the hospital. Randy was receiving an inter venous at the treatment. When I arrived the nurse explained that Randy had got out of his bed from and as he began to walk across the room, the weight of the electric IV pump caused him to stumble. He fell forward, banging his head on the wall. As he fell the IV line pulled out of his vein. He was found, on the bathroom floor unconscious and bleeding from the IV site on his arm. He had a large bump on his forehead, and no one was ever quite sure that he wasn't bleeding there as well. From that point on, I felt it was safer for Randy to have me stay in his room at night.

In January of 1994, Randy's second last hospital stay, for treatment of PCP, he was not responding to the treatment. His doctor told me, he had only about a 5% chance of survival. She suggested that I call our families in so they could spend some time with him. He was not expected to survive the day. She said that she had already spoken to Randy and that she understood he did not wanted to be kept alive artificially however, if he was placed on a respirator, his chance of survival would

improve by about 15%. She told me we had about 15 minutes to make this decision. Although Randy was heavily medicated, he was still awake and somewhat alert. I asked him if he wanted to be intubated, be put on a respirator. He asked me if he would be able to talk while he was on the respirator. I told him no. He said that he didn't want to die while on a respirator; if he was going to die, he wanted to be able to say goodbye to all of us. He told me that I should decide what I thought was best. I was 37 years old and had to take on this responsibility of deciding to try to save his life or to help him to die the way he wanted to die. Randy was always a fighter, so I chose the respirator. Our families arrived and each spent a few minutes with Randy. He was moved to the intensive care unit and placed on a respirator. We were quite literally running through hallways, with Randy in bed, to get him to the intensive care unit. I was shown to waiting area, while Randy was being prepared to be placed on the respirator. A nurse came to the waiting area to give me Randy's cane, which had been placed on his bed. As she started to leave the room, I said, "Wait!" I asked her if Randy was actually on the respirator yet. She said no, that it would be about 5 or 10 more minutes. I asked, "Can I see him for a minute? I didn't kiss him goodbye." She told me we had to hurry. We ran down the hallway to the ICU. I was allowed to be with him long enough to tell him that I loved him, that I would see him a little later and to kiss him. I stood outside the ICU and wept. I thought I would never stop. I recall sliding down the wall I was leaning on, and just sitting on the floor, weeping. I was not ready or prepared for Randy to die. It took about a week before Randy began to respond to treatment. In that short week, I experienced helpless weeping, a sort of abject acceptance that he would die, slight hope as he began, little by little to improve and jubilation when his doctor told me he was fully responding to treatment. He was on the respirator for about 12 days. He was moved out of ICU, back to the ward. During this time, I left the hospital only twice, for a few hours each a time. While Randy was in intensive care, I mostly sat at his bedside, reading or talking to him. I learned how to bathe him and how to wash his hair. His sister Kim brought in a portable tape player and head set so he could listen to his favorite music. Randy did not want Gus to see him in the intensive care unit, so any time I spent with Gus, was either in the hospital cafeteria or in the family waiting area. Gus did not see his father for nearly a month.

Randy never fully recovered, however we were ecstatic that he was home again. About 2 months after he came home, I noticed that he did look or seem well. I called our doctor and described Randy's condition. He said he thought I should bring Randy to the hospital to be admitted. When I told Randy, he started to cry and said he didn't want to go back to the hospital. His birthday was coming up; his family was coming to visit to celebrate with us. We both knew, without saying it, this would be Randy's last birthday. He finally agreed a few hours later. He was jaundiced and seemed to be developing PCP again. He did spend his birthday in the hospital. I said earlier that Randy loved music. He was a big fan of the band Pink Floyd. I had purchased tickets for a Pink Floyd concert in Montreal, to give him as a birthday gift. We had a small party in the hospital to celebrate his birthday. While his family was still visiting him, I took Gus home. While I was driving home, I decided that I would take him to the concert in Montreal. I made plane and hotel reservations for that

night. I packed a suitcase for both of us. I drove back to the hospital and told Randy's doctor of my decision. He had been in the hospital for about 2 weeks. She reluctantly agreed. I checked him out of the hospital, and we went to Montreal. We were able to get backstage passes and Randy actually met the band. He had a wonderful time at the concert. I was frightened the whole time that he would die, but I just kept telling myself that if he did die, what a way to go; in a city he loved, seeing and meeting a band that he loved.

Randy died 2 and a half months later, shortly after noon at home in our bed with me, surrounded by family.

Since I was diagnosed I have had some AIDS related illness. I had bacterial pneumonia, oral and vaginal yeast infections, shingles, and as I said earlier, I am in a constant struggle with wasting syndrome. I have already described many of the drug related side effects. I take on average 40 pills each and every day. I take 9 different prescription medications and 4 non prescription supplements. Only 4 of the medications I take are for the treatment of HIV infections. 4 are for treatment of the cardiac disease I now have, which may be drug related or may be HIV related. One prescription all the 4 supplements are to help cope with side effects from the drug. This is what I need to take to stay alive. This is what I take while I am well.

4. CONCLUDING STATEMENT

Please share any other impacts not previously above.

The secondarily infected group filed an information charge with the RCMP at the start of its criminal investigation of the Canadian Red Cross Society. At the time the criminal investigation began, I spoke publicly about my belief that the investigation would proceed accordingly. I was concerned that if charges were laid the outcome of a trial would not be fair or just. I believed it would be difficult for some to be able to move beyond the reputation of the Canadian Red Cross Society. I was concerned that some would only be able to see the Canadian Red Cross Society as a charitable organization, doing good work. I have said before and I think it bears repeating today, if a flood or some other disaster occurs, the Red Cross is there with food, coffee, blankets, support and comfort. The disaster that hit my life was the Red Cross. No blankets, coffee, support or comfort for me. I have worked very hard during the past 12 or 13 years to raise public awareness about this issue of the safety of Canada's blood supply. I believe that without accountability within that system, there will not be safety.

I and others like me have endured a history of being forgotten, ignored and not recognized as an at risk group.

I and others like me were forgotten, ignored and not recognized by the Canadian Red Cross Society as needing information to assist us making, quite literally, life or death decisions.

I and others like me were forgotten, ignored and not recognized by the Federal, Provincial and Territorial governments, with the exception of Nova, as requiring equal financial compensation for the harm done to us.

I and others like me were forgotten, ignored and not recognized by the Justice system as a group worthy of justice for the harm done to us.

This matter has impacted my life in another way which affects the essence of who I am as a person. I believe the ultimate protection a person receives in Canada is that when a crime is committed against them, the state will prosecute the offender. People can not commit crimes or kill and get away with it – no matter how wonderful or charitable to others they may have been. Without the safety and protection of one's community, life is expendable; a person is worthless. I did not receive safety and protection from the Canadian Red Cross Society.

When the criminal charges against the Canadian Red Cross Society were dropped, and this sentence was agreed upon, I was judged by you, Prime Minister Paul Martin, Justice Minister Cotler, the Ontario Ministry of Justice, the prosecutors John Ayre and Karen Shea to be worthless.

This will be the most difficult message from this court and the justice system to take home to Gus: both my life and his father's life are worthless.