This is the 1st affidavit
of Pieter [redacted] this case
and it was made on 26 Aug 2011

No. S112688
Vancouver Registry

IN THE SUPREME COURT OF BRITISH COLUMBIA

BETWEEN:

LEE CARTER, HOLLIS JOHNSON, DR. WILLIAM SHOICHET, THE BRITISH COLUMBIA CIVIL LIBERTIES ASSOCIATION and GLORIA TAYLOR

PLAINTIFFS

AND:

ATTORNEY GENERAL OF CANADA

DEFENDANT

AND:

ATTORNEY GENERAL OF BRITISH COLUMBIA

INTERVENOR

AFFIDAVIT

I, PIETER [redacted] retired construction worker, [redacted] SWEAR (OR AFFIRM) THAT:

1. I have personal knowledge of the facts and matters hereinafter deposed to, save and except where same are stated to be made on information and belief, and where so stated, I verily believe them to be true.

2. I am 63 years old. I was born in Holland in April of 1948, and moved to Canada with my wife in 1973. I have been living in the Vancouver area since 1973 with a 4 year stretch living in the Netherlands in 1984-1988.

3. I have been married to my wife, Helena [redacted] for 38 years. She works as a Warehouse Manager. We have two children, ages 34 and 35 and two beautiful grandchildren.

4. My career was in construction. I built pre-engineered, prefabricated buildings, which are buildings that are manufactured in sections in a plant and then assembled on site. I worked mainly in Vancouver but I did jobs all over British Columbia and the Yukon. I have been on Disability Assistance since I left my job in 1998.

Discovering I had Huntington's Disease

5. Huntington's disease ("HD") is a genetic disorder that is passed down through families. Everyone who has the gene will eventually develop the illness, which causes nerve cells in the brain to waste away. This progressive degeneration of brain cells results in a variety of symptoms, including uncontrollable movements, behavioural changes, as well as cognitive and psychiatric disorders. There is no cure for this disease.

6. I chose to get tested for the gene for HD in 1993, which was the same year my mother died of HD. I knew there was no cure, but I wanted to know what the future held for me and my family.

7. Learning that I had the gene for HD did not have an immediate impact on my life. I was asymptomatic in 1993, and I knew it might be years before I actually developed the disease. Indeed, the progression of my symptoms was gradual and I was able to work for five years following the discovery that I had the gene.

8. Once I discovered that I had the HD gene, I began going to the Centre for Huntington's Disease at the University of British Columbia (the "Clinic") for annual check-ups. The Clinic's staff includes a geneticist, two neurologists, a psychiatrist, a neuropsychiatrist, and a genetic counsellor. My annual appointments involved a variety of assessments to determine if the disease's onset had begun.

9. Over the years, the Clinic has provided me with information about clinical trials. I have participated in a number of trials because I want to help find a cure for this disease. I participated in a trial that researched the effects of high-concentration fish oils on the progression of HD. This study was discontinued because there were insufficient positive results to justify its continuation. My wife and I both participated in TRACK-HD, which is a major international study seeking to identify the best combination of assessments to be used in clinical trials of

disease-modifying treatments. Volunteers for this study included people who are asymptomatic, people in the early stages of the disease, and a control group of individuals who do not have the gene. Both my wife and I underwent assessments, MRIs and other neurological tests as part of the study. We participated in the study for two and a half years. I am currently participating in a double-blind trial based on enzymes which is scheduled to last for 5 years.

10. I feel fortunate that my HD onset took place later in my life. Not everyone is so lucky. Young people can also have HD, and it will likely lead them to an early death. It is important to me that I contribute in some way to the prevention of suffering and loss by helping advance the state of medical knowledge.

Progression of HD Symptoms

11. I was officially diagnosed with HD in 1998 once I began developing symptoms. By then, my HD symptoms had reached a level that made me unable to produce the quality of work I was used to. For example I would measure what I had to cut and by the time I got to the saw, I no longer knew what I was doing. On a number of occasions, I called my wife from worksites because I was confused. I did not know where I was going and what I was needing to do. The most important thing to do was to create a day without any impacting stresses.

12. I spoke with my employer and told him about my diagnosis. I was told I could finish the job I was working on and was given the opportunity to leave in a dignified way. Under the circumstances, I am grateful that I was not fired.

13. The year following my retirement was, perhaps, the hardest time for me. I felt guilty watching my wife go to work, knowing that I could not help contribute financially. It was also difficult to watch other people retire and enjoy their old age. I was envious of their circumstances. My perspective has changed over the last few years as I have watched others endure hardships, but it was a struggle at the time.

14. I dealt with this difficult period by keeping myself busy. My wife and I bought homes, which I would renovate, and then we would re-sell them. I was able to do this work because I could take my time and did not need to rush. It gave me a sense of accomplishment and made me feel like I was still able to contribute to our family.

Progression of Symptoms

15. My initial HD symptoms were mainly cognitive. I struggled with depression, anxiety, agitation and memory loss. In 2007, I had to stop driving, which was a great blow to my independence and mobility. Losing the ability to drive felt like an amputation. I am now largely dependent on my family for transportation, though I do occasionally take taxis or HandyDARTs.

16. My physical symptoms took longer to appear, but they are progressing and have become more apparent each year. For example, I began losing my balance and falling about six or seven years ago. In 2007, we had to sell our house because the house had stairs, and they became impossible for me to navigate. Our current home does not have stairs.

17. Currently, I experience involuntary movements. I have difficulty speaking and I frequently make jerky and uncontrollable movements. I am coping with anxiety, and memory loss. I take the anti-depressant Zoloft and the anti-psychotic Mementine, which is commonly used to treat Alzheimer's. The medication has successfully treated my depression, but it can be challenging to treat my symptoms and maintain a balance between alertness and sedation.

18. The hardest part of the disease for me is that I am no longer able to communicate and interact with people the way that I used to. The disease affects my motor skills, so my ability to enunciate is significantly impaired. This is exacerbated by the disease's effects on my cognitive abilities, which makes it difficult to form sentences in my mind fast enough to express myself. I experience ongoing frustrations with my inability to participate in debates and lively conversations, something that I used to be very passionate about. I have a very strong relationship with my wife and children, but it can sometimes be difficult to form new relationships. For example, sometimes it is hard for me to watch others interact and communicate with my young grandchildren because I see that they are able to build relationships with them in a way I no longer can. I wonder what my relationship with them would be like if I did not have this disease.

19. I am grateful that I have not become aggressive or violent, which are both common consequences of this illness. HD can cause significant personality changes, and I am glad my symptoms have not become that severe. Not all of my experiences with HD have been negative.

I have friends and loved ones who have died before me or endured hardships that are unrelated to HD, so I do not feel like the victim of some injustice. My symptoms continue to progress and I feel myself getting worse each day, but I still consider my quality of life to be good.

Family History of HD

20. HD is very prevalent in my family. There are at least 10 members of my family who currently have HD; many are in denial and refuse to get tested. I was recently at a family reunion and a relative's face was badly bruised because she kept falling. She could not understand why her balance was so poor. She had been tested for many disorders and diseases, but she refused to get tested for HD even though genetically it is very likely that she has the disease.

21. Perhaps the most disturbing experience I have had with HD was watching my mother deteriorate. Although my mother lived in Holland, and my wife and I lived in Vancouver, we saw her frequently. My mother was a proud and strong woman who in her final years was reduced to a mess by the disease.

22. My mother was officially diagnosed with HD around 1985, but I suspect the disease's onset was actually when she was in her late 40s. My mother told the family about her diagnosis but then never discussed it again. Both my parents were in denial about my mother's illness. They never sought help. My mother's illness was hell for my family. The disease made her angry and violent. She blamed her anger and hysteria on everyone and everything, but HD. The last time I saw her, she was rather demented. She would have been unrecognizable to her former self.

23. Along with the violence and hysteria, my mother's motor skills and coordination were also affected. She fell frequently and broke many bones. She was buried with her arm in a cast. My mother died in 1994 at the age of 68. I suspect that she ultimately gave up on her life and starved herself to death. I feel a lot of guilt that I did not know more about HD while she was alive. I blamed my mother for her anger and madness without realizing that these are symptoms of the disease.

24. My uncle also had HD. His wife looked after him for 18 years before he was eventually hospitalized. She visited him in the hospital every day. At one point she had to get heart surgery and could not visit him for two weeks. He was incredibly agitated and confused. It was terrible to see. He spent the last two or three years of his life in the fetal position in a hospital bed. He died in 2006.

25. I watched my aunt die of HD as well. She denied ever having the disease, but her symptoms were very apparent. She had physical symptoms such as uncontrollable movements and, similarly to my mother, the disease made her violent. My aunt weighed less than 35 kilograms at the time of her death. My brother was just diagnosed with HD in May of 2011. My sister refuses to be tested.

26. My children have both been tested for HD and they do not carry the gene. This means that none of my children or grandchildren will develop this disease. It is a profound relief.

Choice in Dying

27. My wife and I occasionally discuss my death because my deterioration is inevitable. We both have a good understanding of what lies ahead, but our current focus remains on living with HD.

28. I cannot tell you when I will want to stop living. At this point, I still want to live, but when the quality of my life is gone, I want choice in my death and the right to choose the time and manner of my dying. I have not drawn any lines. However, I have completed a "Do Not Resuscitate" (DNR) request and I know that I do not want a feeding tube if I lose the ability to swallow.

29. Right now, I feel well supported. My wife helps me keep a healthy perspective and encourages me to find the humour in my challenges. We are both part of HD support groups, which enable us to connect with others who are going through similar challenges. Unlike cancer or many other diseases, HD is not a painful illness. I think my outlook on life would be different if I was in pain.

30. I am very concerned about preserving my dignity. I have sufficient experience watching loved ones deteriorate with HD and I am well aware of the things I have already lost to the disease. I am confident that one day I will reach a point where I have had enough. I trust that I will recognize that day when it comes. I know that I do not want to waste away like my aunt or spend years in a daze in a hospital bed like my uncle. I know I do not want to suffer through a degrading demise like my mother.

31. I come from the Netherlands, where medically assisted dying has been legal for many years. I believe that this is a sane and sensible approach. I support medically assisted dying because it prevents needless suffering. I see this issue as being fundamentally about the right to choose and the right to have that choice respected. I believe that it should be an individual's choice, not the government's choice.

32. I have watched people struggle to end their own lives. I had a friend with HD who tried to kill himself by driving his car into an electrical pole. He survived with only a broken leg. He eventually starved himself to death in the hospital. Dying of starvation is a terrible way to die, yet the doctors and medical staff respected his request to die in that manner, though they would not help him die in a less painful way.

33. There could be a long road ahead of me. Most people who have this illness die from other causes. I am not sure if I would end my own life if the laws do not change in Canada. I do not want to put my family in a position where they have to break the law to help me. I do not want any member of my family to face possible criminal charges. I do not want my wife to face the opposition of her family, which is religious, should she decide to help me die. I do not want to be forced to take my own life in a violent manner that would traumatize my family. I want the decision to be legal, balanced and clean. For myself, I would prefer clear rules and safeguards. I do not want to have to make this decision without medical advice and assistance.

34. When I no longer have a life of quality, I want to have the choice to end my life with dignity and under the care of a doctor. I want to be able to end my life in peace, having the chance to say goodbye to my family.

SWORN (OR AFFIRMED) BEFORE ME)
at Abbotsford, British Columbia, on)
26 Aug 2011)
)
)
A Commissioner for taking Affidavits for)
British Columbia.)

PIETER [redacted]

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AFFIDAVIT

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