This is the 1st affidavit
of Jonathan [redacted]
[redacted] Jul 2011

No. S112688
Vancouver Registry

IN THE SUPREME COURT OF BRITISH COLUMBIA

BETWEEN:

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

PLAINTIFFS

AND:

ATTORNEY GENERAL OF CANADA

DEFENDANT

AND:

ATTORNEY GENERAL OF BRITISH COLUMBIA

INTERVENOR

AFFIDAVIT

I, JONATHAN [redacted] retired welder and fabricator, of [redacted] SWEAR (OR AFFIRM) THAT:

1. I have Huntington's disease ("HD") and as such 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 a 52 year old retired welder and fabricator. I have been married to my wife, Karen, for 22 years. We have three boys, ages 18, 16, and 10.

3. I worked as a metal welder and fabricator for my entire career. I started working in the trade when I was about 18 years old, and developed a specialization in aluminum and steel

fabrication. My work entailed building various industrial metal structures by cutting, bending, and assembling aluminum and steel.

4. Over the years, I have worked for a number of different shops. I did a significant amount of work building and fabricating boats and ships. For about eight years, I worked for Allied Shipbuilders Ltd. in North Vancouver, British Columbia. One of the major projects I worked on involved fabricating high speed passenger/vehicle ferries for a contract for BC Ferries. After the fast ferry project was completed, I went to work for Adrenalin Marine Ltd. in Delta, British Columbia. I worked there for about four years. Most recently, I worked with Advance Engineered Products Ltd., in Surrey, British Columbia, building aluminum semi-trailers and tankers. I worked there for a little over a year before I decided to retire in 2008 due to complications from HD.

Testing and Diagnosis with HD

5. I was tested positive for the gene for HD around 2001. I was not experiencing any symptoms at the time. My mother had HD so I knew I had a 50 percent chance of inheriting the disease from her, so I decided to get tested. My main reason for taking the test was that I wanted to know if there was a possibility that my children might have the gene. If they did, I wanted to know if there was something I could do for them early on.

6. I went to a clinic at the Centre for Huntington Disease, which is part of the University of British Columbia, Faculty of Medicine (the "Clinic") for the blood test. They automatically give you the test if you have a family history of HD. They told me I tested positive.

7. When the Centre told me I tested positive, I was really shaken up. I felt mentally and physically blown away. It felt like I was in the afterburner of a jet engine. It was a pretty tough time. At first, I only shared the bad news with my wife. I did not tell other family members right away because I did not want my mother to feel badly that she had passed the gene on to me. Now my two oldest sons know that I have HD; my wife and I are waiting to tell our youngest son until he is a little older.

8. I worry about my kids and whether they might carry the gene. I told my oldest boys that it was their choice whether or not they wanted to get tested. They decided not to get tested yet. I have two brothers. They have not been tested, but luckily neither of them has any symptoms.

9. Shortly after my diagnosis, I met with individuals at the Clinic who provided me with information about HD and offered me support services. The Clinic has a team of specialists to serve HD patients, including geneticists, neurologists, psychiatrists, and a genetic counselor. I have been going to the Clinic since I was first tested. At least once a year, I go to the Clinic and attend a full day of appointments where I meet with a variety of specialists who conduct assessments and inform me about new research and clinical trials. About five years ago, when I was having a lot of trouble with my symptoms at work, I went to the Clinic about every six months.

10. The British Columbia Huntington's Disease Resource Centre ("Resource Centre") is located at the Centre. After I learned I had HD, I met with Susan Tolley, the director of the Resource Centre, and another counselor at the Resource Centre, and they told me that she could help me and my family by providing us with information about the nature and course of HD, techniques of care, and research progress and counseling. Over the years, I have accessed the Resource Centre's counseling and informational services and have attended retreats for people living with HD hosted by the Resource Centre.

Progression of HD

11. As soon as I received the news that I had the gene for HD, I decided to work as much as possible, because I knew from my mother's experience with HD that I might not be able to work much longer.

12. For awhile, I did not experience any symptoms, but within about one or two years after I was tested, I started to notice that my hands felt stiff, like they were freezing up. As a welder, I did a lot of work with my hands, so when my hands were stiff and cramping it interfered with my work quality. Once my hands started freezing up, it was hard to make even, long welds. I had to keep starting and stopping during the welding process which caused the welds to come out deformed with ugly cracks and lumps.

13. I also started to feel little twitches in my extremities and muscle cramps. Occasionally my speech became slurred. I started to have trouble sleeping at night. It was difficult to fall asleep, and even when I succeeded, I would wake up several times during the night. I was tired at work the next day. At my last job, I worked in alternating shifts from 7:00 a.m. to 3:00 p.m. for two weeks, and then 3:00 p.m. to 1:00 a.m. for two weeks. As my symptoms progressed, it became difficult to keep going back and forth between these two shifts.

14. I could also sense a change in my mood. I started to feel depressed and distracted. Depression is an early symptom of HD. It became difficult for me to focus on my work. Complex welding and fabricating involves a lot of multitasking and problem solving and requires a high level of concentration. My head just was not in it anymore. Things that used to be easy for me became hard. For example, at my last job, my boss asked me to modify the back of a fishing boat by extending the house. Before my diagnosis, I would have had no problem doing that, but when I got down to starting the job I could not figure out how to go about doing it. I just could not think straight. I was worried that I would be fired if I told my employer about my disease, so I just had to muddle through it.

15. Around 2007, a counselor at the Resource Centre recommended that I consider an early retirement. I felt like my work was not good enough for the job and I was no longer proud of the quality, so I knew it was time to stop working. The Resource Centre helped me apply for disability insurance and my pension. I retired with a small pension in 2008.

16. Over the past three or four years, my involuntary twitching and jerking movements have worsened. I started to experience a bit of twitching several years ago, but it happens a lot more now. I also have muscle stiffness in my hands and calves. Sometimes my hands feel like little clubs. A couple of years ago, I started to experience severe leg stiffness and cramps. The cramps wake me up at night.

17. I still have a lot of trouble falling asleep at night. I try to tire myself out during the day through physical activity in order to prepare myself for sleep so I can get a better night's rest, but lately it has not been helping. Almost every night I lay awake in bed for what seems like the longest time.

18. I sometimes have difficulty producing speech and slur my words. I have started to have trouble making decisions and planning, organizing and prioritizing tasks. I am still capable of doing all my household tasks, but sometimes it takes me awhile to get a project done. For example, I need to spend more time planning what food we need, making lists, and buying groceries. Sometimes I have difficulty focusing on a task for long periods.

19. I do not take any medications or anti-depressants for my disease. I am one of the few people I know living with HD who is not on anything. If it gets to a point where I need medication, I will take it, but for now I prefer a non-medicated approach to my health. I do not want to end up heavily sedated like my mother was at the end of her life. I do not want to end up groggy during the day because I took sleeping pills to go to sleep at night. One way I manage the illness has been through improving my eating habits. I was not eating very well when I first started experiencing symptoms, but I developed better habits. Now, I have a lot more energy.

20. HD is a disease that takes you piece by piece. It is not fun. There is a constant decline. I worry about what functions and activities will become more difficult next. It is unsettling and anxiety-producing. I calm myself by telling myself that I will deal with any problems when they happen. I try not to think about the progression of the disease too much. I take things as they come.

21. I am trying to stay positive and to focus on this stage of my life. I am still figuring out how to keep myself occupied after giving up my job. I am trying to come up with my "Plan B." The most positive thing that has come from the disease is that now I get to spend a lot more time with my kids. When I worked afternoon shifts, I missed out on seeing them in the evenings. I am taking it all in now while I can. I help them get ready for school and I am waiting for them when they come home. We eat dinner together as a family. We might go on a camping trip this summer.

22. I have also started doing different hobbies. I have been working on an old Dodge Dart and plan to put a new engine and exhaust into it. I am thinking of taking up a small welding project. I do not want to stop welding completely, even if I can no longer do it as my career.

23. I have also started watercolour painting. I took it up after I attended a retreat for people with HD that was sponsored by the Resource Centre and the group encouraged me to do more artwork. I have always had a bit of an artistic side. I used to sketch drawings at work in order to explain concepts or show fabrication details. Recently, I have been painting and drawing landscapes.

Family History of HD

24. I know that my disease will progress and that next year it could be a lot worse. My mother, my maternal grandmother and a couple of aunts had the disease. Our family went to England to visit my grandmother a couple times when I was a kid. I remember noticing, even at a young age, that there was something wrong with her. She would always be swaying because she could not keep her balance. Her body jerked and her speech was slurred. She became bedridden and died from a heart attack, which is a common complication of HD.

25. My mom suffered from the symptoms of HD for about 20 years. She died a few years ago, when she was about 58 years old. For many years, she could not walk without help. She broke her hip once after a bad fall. It was hard to take her out so she never really left the house.

26. For the last five years of her life, she was heavily sedated with drugs, so she was always in bed. Eventually, she needed assistance with eating and drinking. She could not walk and had difficulty sleeping. She was incontinent. Her personality changed. She had dark thoughts and was not mentally aware of her surroundings. At the end, she just kind of gave up. It was pretty tough to watch. I felt sorry for my mom.

Choice in Dying

27. I do not want to end up like my mom, just sleeping and eating, slowly going crazy. Right now, my condition is not that bad. I am lucky. I am relatively healthy. I still get a lot of enjoyment out of life and life is good and worth living. But I know that the disease will progress in the coming months and years. If I reach a point where I need help to do everything and am trapped in a chair or a bed for months and months, I will want to have the option to end my life.

28. I have not given a lot of thought to how or when I would like to die. I am still adjusting to the fact that I have HD and I am trying to stay focused on my "Plan B."I cannot predict what will happen in the future. However, I believe I should have the right to a medically-assisted death if that is what I choose when the time comes.

29. If I decide that I want to end my life, I would not want to end my life violently. I would not want to impose that trauma on my family members or risk a prolonged and gruesome death. The law forces me to make a horrible choice. If my family members helped me end my life, or were present when I died, they might risk facing a criminal investigation and prosecution. I would never want to jeopardize them in that way. I believe I should have the right to a peaceful, dignified death, and that I should be able to protect my family from coming to any harm in the process.

30. I have seen a lot of people suffer at the end of life. These experiences have impacted how I feel about my own disease and my end of life choices. About ten years ago, a good friend of mine died from Lou Gehrig's disease. It was tough to see him at the end of his life and to witness his decline. He was completely incapacitated. He could not move. He was confined to wheelchair that held his head up. He could barely speak. He was mentally present but his body no longer functioned. He seemed trapped.

31. I believe I should have the right to end my life with dignity and under the care of a doctor if I decide that my suffering is unbearable. If it ever gets to that point, I should have a say in when and how I go because I am the one who must live with this disease.

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

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JONATHAN [redacted]

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INTERVENOR

AFFIDAVIT

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